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ABSTRACT

The report describes the population of children in Australia with spina bifida and/or hydrocephalus, notes their needs and characteristics, reviews their school placement and social circumstances, and considers future educational services for them. Initial chapters review the literature on medical, psychoeducational, and social-family aspects of the condition. A chapter on the treatment and early management of spina bifida is followed by a summary of a study of spina bifida and hydrocephalus in 130 children in Queensland. The study examined parental experiences at birth and hospital experiences throughout childhood. A study of the status of children with spina bifida and hydrocephalus in regular and special schools draws information from classroom assessments and teacher reports on such aspects as self-care, cognitive skills, and academic achievement. Another study features analysis of fine motor difficulties in this population. Interviews with 130 parents reveal information on management and schooling issues. Two final chapters address issues of long-term care and the future of schooling for these children. (CL)

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AUSTRALIA

The Management and Education of Children with Spina Bifida and Hydrocephalus

R. J. Andrews and J. Elkins

ERDC Report No. 32

Education Research and Development Committee

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Education Research and Development Committee

THE MANAGEMENT AND EDUCATION OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS

ERDC Report No. 32

Robert J. Andrews and John Elkins

With contributions by Denise C. Elkins

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PREFACE

The pattern of disabilities in children is continually changing. For example, in the case of children experiencing physical disabilities, the conditions of tuberculosis and infantile paralysis and the effects of generalised malnutrition are no longer important causes of disability in developed countries, and an earlier rapid increase in the numbers of children surviving with cerebral palsy has in recent years been almost mirrored by those surviving with spina bifida.

The implications of these changes for society are numerous. They are important to social and educational planning and to the provision of services. In the educational area, for instance, there are implications for the number of educational places that are required in special schools, the building and modification of facilities, and the provision and training of staff.

In recent years there has been a rapid increase in the number of children surviving with spina bifida and/or hydrocephalus. This is in no small way due to advances in medical science. Today, increasing numbers of children with these conditions are enrolled in regular and special schools and even greater numbers, in proportion to the schoolage populations, are receiving services leading up to school enrolment.

It was a lack of information about the numbers and characteristics of these children, their educational needs and placement, family circumstances and management, which prompted us to undertake the research which has led to this report. Evidence was emerging to indicate that in Queensland, for example, numbers of children identified because they manifested spina bifida or hydrocephalus, and therefore experienced fairly severe handicaps, were enrolled in regular schools. Unlike the deliberate integration of cerebral-palsied and sensorily handicapped children into regular schools, these children were being integrated in a fairly natural way, and apparently largely due to the efforts of parents and teachers. This pattern of schooling broke the more traditional development of special segregated schooling for children with severe disabilities.

The purpose of our investigation, therefore, was to describe this population of children, examine their needs and characteristics, their school placement and social circumstances, and to consider future educational services for them.

The project was motivated by discussion with Barbara Buttfield, at that time a social worker with the Spina Bifida Association of Queensland; Geoffrey Swan, Inspector of Schools (Special), Division of Special Education, Queensland Education Department; Leigh Atkinson, Visiting Neurosurgeon at the Mater Children's Hospital; and Simon Latham, Deputy Medical Superintendent at the Royal Children's Hospital. Barbara Buttfield later contributed directly to some stages of the research as a Senior Research Assistant. The other members of the planning group continued to collaborate with the authors throughout the project. The concern and efforts of Geoffrey Swan for handicapped children, which gave the initial impetus for the research, are especially acknowledged.

In the preparation of this volume we are especially indebted to John Burge and Elizabeth McDonnell, who worked tirelessly on sections of the research and review of the literature when on study release from the Queensland Education Department. Barbara Buttfield assisted in similar ways. Others also gave direct assistance. An advisory committee to the project included, in addition to those persons mentioned above, Winifred Apelt (Schonell Educational Research Centre), Patrick Briody and Sidney Cliffe (Queensland Education Department) and Rosemary Turner and Mary Smith (Spina Bifida Association of Queensland). Assistance with various aspects of the project was also given by Rodney Campbell and Beulah Middleton while attached to the Centre in 1977, and by Naomi Hardy, Beverly Henwood, Ron Parry and Ann Jobling.

The early research was a collaborative venture. Funding or other material support was provided by the Education Research and Development Committee, the Queensland Education Department and the Spina Bifida Association of Queensland. Valuable encouragement was provided by the Education Department and its officers in the provision of every assistance in the identification of children and data collection. Numerous school principals, teachers, guidance officers and others provided this information and gave of their time to assist the project.

Other agencies which gave valued assistance were the Queensland Health Department, Queensland Society for Crippled Children, Xavier Hospital for Children, North Queensland Society for Crippled Children and Multiple Handicapped Association of Queensland. The authors sincerely acknowledge their support. Of equal value were the time and interest of the children's parents, who readily assisted in providing information, and the contributions of the children in whose interests this study was undertaken.

Special acknowledgment is made of the permission given by the Spina Bifida Association of South Australia to reproduce the figures in Chapter 2 and of the expert contribution of Wendy Barrie in compiling drafts and tables and preparing the final manuscript.

R.J. Andrews
J. Elkins

Fred and Eleanor Schonell Educational Research Centre
University of Queensland
December 1980

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CHAPTER 1

INTRODUCTION

Recent surgical techniques designed to ameliorate the effects of the group of conditions commonly known as spina bifida (especially myelomeningocele) have resulted in the survival of increasing numbers of children experiencing this condition. The reported incidence, though variable, is between 1 and 2 per 1000 live births and the survival rate is better than 1 per 1000. The educational implications of the disorder are very complex, rivalling those for children experiencing cerebral palsy, which has been regarded as the greatest crippling condition in children and that with the most complex educational implications. Medical complications associated with spina bifida include hydrocephalus, paralysis of the legs, and loss of control over bowel and bladder functions. The compounding effects of immobility and incontinence on social interaction and educational provision are obvious. Little research on the management and education of children with spina bifida or hydrocephalus has been undertaken in Australia. There is a particular lack of case study and descriptive investigations and studies looking at the implications of these conditions and their management in an educational setting.

Spina bifida is a congenital malformation of the spine. It is the most common of a number of neural tube malformations. In its more serious forms it is a condition that is visible immediately a baby is born, and medical diagnosis is not difficult. However, the effects of the condition vary from a very minimal disability to severe handicap, and the educational implications of spina bifida are just as variable. Tew (1973) lists 4 types of spina bifida (see also Figure 1.1):

(a) *Spina bifida occulta*. This very mild form is sometimes associated with enuresis, but is generally known to have no medical or educational significance.

(b) *Meningocele*. The spinal cord coverings are exposed. After the lesion has been repaired, children with meningocele are usually indistinguishable from other children, at worst having slight limps or minor visual defects. Hydrocephalus can occur with meningocele.

(c) *Myelocele*. Also known as myelomeningocele or meningomyelocele; the nerves lying in the spinal cord are exposed. Between 80 and 90 per cent of children with myelocele also have varying degrees of hydrocephalus.

(d) *Encephalocele*. The lesion occurs on the head, and brain tissue is frequently found in the sac. Repairing the lesion will necessarily involve removing part of the brain.

Types (a) and (b) above are sometimes grouped under the term *spina bifida cystica*. A related neural tube malformation is *anencephaly*, '. . . a condition thought to be related to spina bifida in which the bones of the skull fail to fuse and the underlying brain tissue is very abnormal. It is incompatible with survival' (Anderson & Spain 1977).

Tew, in discussing the increasing importance of spina bifida as an educational as well as a social and health problem, quotes statistics from *The Health of the School Child* (Department of Education and Science 1972) in which a comparison is made between the most frequently known crippling conditions from which children suffer

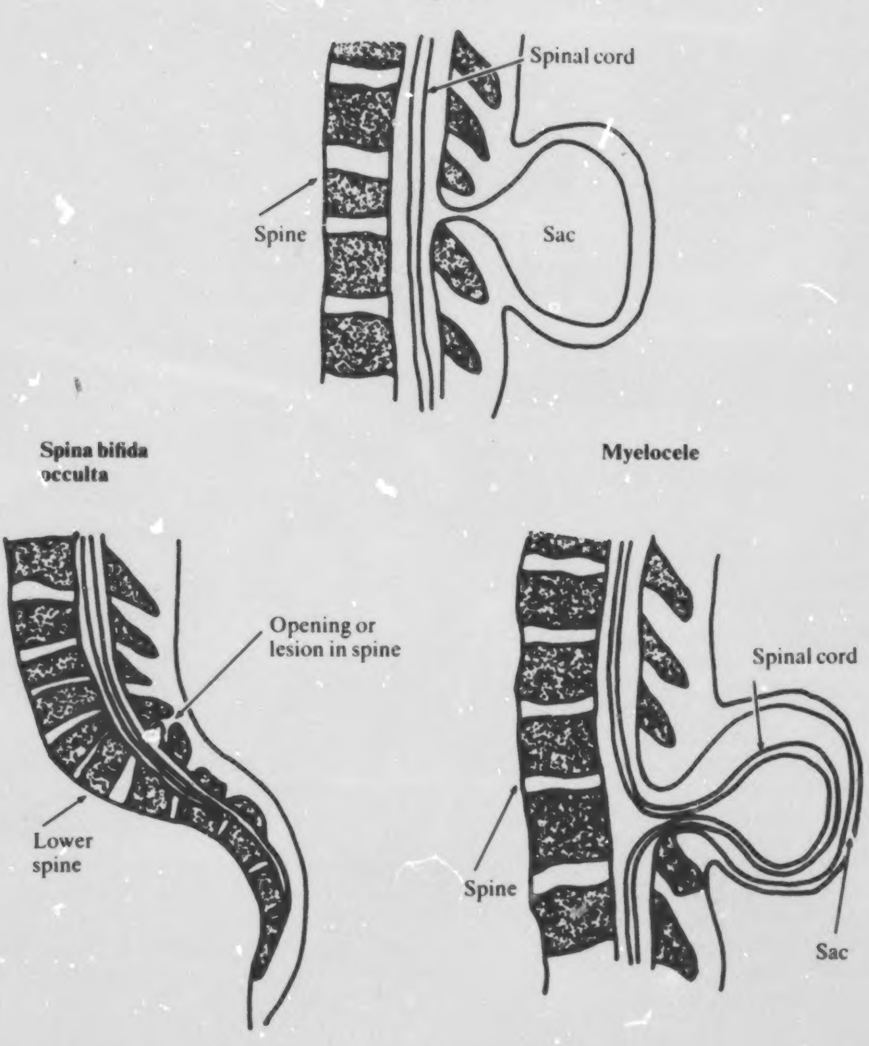
Meningocele
Spinal cord
Spine
Sac
Spina bifida
occulta
Opening or
lesion in spine
Lower
spine
Myelocele
Spinal cord
Spine
Sac

Figure 1.1: **Three types of spina bifida**

in the United Kingdom (see Table 1.1). The increasing significance of spina bifida as a handicapping condition in school children is apparent. Australian data on prevalence have been inadequate, but a study to be undertaken in 1981 by the Australian Bureau of Statistics should provide firm prevalence figures.

The Spina Bifida Association of Queensland has estimated the incidence of spina bifida at between 1 and 2 per 1000 of live births. This incidence is about the same as the estimated incidence of cerebral palsy. The survival rate of spina bifida children is somewhat less, estimated at a little over 1 per 1000.

Table 1.1: **Most frequently known crippling conditions: England and Wales, 1964–70** (*a*)

	1964		*1968*		*1970*	
	No.	*Per cent*	*No.*	*Per cent*	*No.*	*Per cent*
Cerebral palsy	2451	66.4	2765	65.0	2944	61.4
Post-poliomyelitis	674	18.3	442	10.4	316	6.6
Spina bifida	566	15.3	1046	24.6	1533	32.0
Totals	3691	100.0	4253	100.0	4793	100.0

(*a*) The figures refer to physically handicapped schoolchildren in special schools in England and Wales. The table is adapted from that published by the Department of Education and Science (UK), 1972.

At the incidence rate of 2 per 1000, it can be expected that 72 children will be born with spina bifida in Queensland each year, and 454 in Australia, based on live births reported for 1977.[1]

Hydrocephalus is a condition in which excessive amounts of cerebro-spinal fluid accumulate around and within the brain. Usually this fluid is drained off through the various sinuses, but insufficient drainage caused by blocking of the spinal canal may result in hydrocephalus. These blockages may be the result of inflammation, a tumour or malformations of the brain and skull, which exist at birth. Alternatively, blockages may be due to disorders acquired after birth. Hydrocephalus is generally accepted to occur in over 80 per cent of cases of spina bifida. The spontaneous arrest of hydrocephalus may occur, but most children experiencing this condition are treated by insertion of a valve to drain excess cerebro-spinal fluid.

Surgical techniques to improve the survival rate and the quality of life of spina bifida children have been in use in Queensland for some years now. Together with the use of a valve (shunt) to avoid the often fatal consequence of hydrocephalus, these techniques mean that children who once had a short life expectancy, usually in hospital, and were judged not to present educational and social problems, now survive in increasing numbers and live with their families within the community.

In Queensland, a preliminary survey early in 1977 indicated the following distribution of 122 spina bifida and/or hydrocephalic children in schools or of pre-school age (Table 1.2). If children in formal schooling only are taken into account, 49.9 per cent were attending regular schools. These figures may be compared with an earlier survey carried out by Swan (1974) which indicated that 78 per cent of spina bifida children were in regular schools, and the balance in special schools.

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[1] These estimates are based on the live births for Queensland and Australia reported by the Austrlian Bureau of Statistics for the year ended June 1977 (catalogue No. 3212.0).

The children in Swan's survey ranged in age from 6 years 4 months to 15 years, and their intelligence quotients ranged from I.Q. 54 to I.Q. 107, with a median of 79. Most of the children enrolled in residential special schools were reported to require constant attention. About one-third had difficult family relationships in that (a) the parents were unable or unwilling to cope with the physical handling of the children, (b) visits to the children during term time were infrequent or (c) difficulties were experienced during vacation periods at home.

However, some parents of spina bifida children have done very well in maintaining and caring for their children at home and in regular schools. They provide transport to and from school, and prevent infection — a major problem with spina bifida children — by ensuring that their incontinence is medically attended to and that the teachers and other children understand the difficulties.

Table 1.2: **School placement of 122 spina bifida and hydrocephalic children in Queensland in 1977: a preliminary survey**

School placement	*No.*	*Per cent*
Regular school placement		
Pre-school	6	4.9
Primary	40	32.8
Secondary	3	2.5 (40.2)
Special school placement		
Xavier	18	14.8
Montrose	15	12.3
Cootharinga	10	8.2
Narbethong School for Visually Impaired	1	0.8
School for Deaf	1	0.8
School for Multiple Handicapped	1	0.8
State School for Spastic Children	1	0.8
Aitkenvale Opportunity School	1	0.8
Maryborough Opportunity School	1	0.8
Rockhampton Opportunity School	1	0.8 (40.9)
Other placements		
Not yet in pre-school, or placement unknown	23	18.8 (18.8)
Totals	122	100.0

Referring to the educational needs of spina bifida children, Tizard (1966) has written:

> The social and educational problems of children with spina bifida are extraordinarily complex in themselves, and they are made more difficult because of two additional factors. First, although many children with this condition have survived in the past, we still lack really adequate epidemiological data concerning how they progressed and what happened to them. Secondly, new operative techniques are increasing the proportion of survivors, but at the same time they seem also to promise the alleviation of many handicaps now recognised as secondary. Thus the problem is to some extent a new one. (p. 310)

This statement to the Surgery Section of the Royal Society of Medicine in Britain in July 1966 could well have applied to Queensland in 1978. Incidence figures were available in the United Kingdom because of Registers of Risk, and the first school specially and exclusively for children suffering from this condition was the Mossbrook School, Sheffield, opened in 1966. It had places for 45 children, ranging in age from 2 to 16 years. Parents of spina bifida children in Britain were establishing a parents' organisation about that time, a move now achieved in Australia. In Queensland, a parent group for children with spina bifida was established in 1970, and now provides a wide range of support services to parents and children.

Of the different types of spina bifida referred to previously (page 1), the special educator is mainly concerned with children experiencing encephalocele or meningomyelocele, which together account for 90 per cent of all children born with manifested spina bifida. Although the survival rate is much greater in spina bifida occulta and meningocele, these types do not present problems which are as extensive as the other forms. Before the discovery of effective surgical methods to ameliorate this congenital condition, very few children with encephalocele and meningomyelocele survived. It is only in the last few years that sufficient children born with these conditions have lived long enough to create interest and concern about the educational and psychological aspects of the condition. The growing importance of the problem, and the need for accurate information about the numbers of children and their educational needs, are now clear. However, Queensland, for example, has no Register of Risk, the condition is not a notifiable one and the collection of data presents considerable difficulty.

This report[2] presents the results of a study of the nature and extent of the educational needs of spina bifida and hydrocephalic children in educational programs and in long-term residential care, and how these needs relate to their social characteristics. It also includes an extensive literature review and discussion on management techniques. The major study reported was planned to indicate why many spina bifida children are integrated into regular school programs. Since the presence of these children in regular schools in Queensland was not the result of any planned approach by education authorities, it was hoped to ascertain the factors which surround their acceptance in some regular schools but not in others. A further outcome of the study was sought in a definition of the educational management and needs of spina bifida and hydrocephalic children in relation to education services of the future.

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[2] A more detailed report was submitted to the Education Research and Development Committee in 1979 (Andrews et al. 1979).

CHAPTER 2

A REVIEW OF THE LITERATURE ON SPINA BIFIDA AND HYDROCEPHALUS

2.1 INTRODUCTION

2.1.1 Historical overview

In recent years many medical procedures have been employed in the treatment of spina bifida. As a result, there has been a dramatic increase in the numbers of children with this congenital disability who survive with varying degrees of physical and/or mental disability, and who are to be found in the homes and schools of most communities. Society itself is becoming more aware of the need to develop new approaches and resources to meet the social and educational needs of these children and adults.

The condition known today as spina bifida has existed throughout human history. Lorber (1976), quoting Ferembach (1963), claimed that malformations of the lumbo-sacral vertebrae were common in very old skeletons. Hippocrates, the Greek physician who lived in the 5th century B.C., was aware of the condition. It was Tulp, the teacher portrayed in Rembrandt's *The Anatomy Lesson* (1632), who described and illustrated the disability in 1652, and who first used the term 'spina bifida' (cited in Brocklehurst 1976).

The generic term 'spina bifida' has persisted. It describes the feature common to a large group of malformations—namely, failure of fusion between the arches of the vertebrae, with or without protrusion and dysplasia of the spinal cord or its membranes. The fusion is an important step in the development of the embryo before birth, when the 2 sides of the spinal canal in the back grow together to form the cavity for the spinal cord.

Knowledge of the condition has increased immensely since the seventeenth century and it is now recognised that the defect occurs during the first 4 weeks after commencement of intra-uterine life. In some 80 per cent of cases it is accompanied by hydrocephalus.

Lorber (1976) outlines 5 phases in the history of treatment of spina bifida:

(a) Until the late nineteenth century, no treatment was possible. The majority of children born with the condition died in early infancy.

(b) By the late nineteenth century, 2 approaches to treatment were attempted. The first was to inject iodine into the spina bifida sac. The second was an approach involving surgical excision and closure of the lesion. Both techniques were abandoned.

(c) Between 1938 and 1958 a highly selective approach was undertaken at a few specialised treatment centres. Most infants were untreated unless they had survived for 18 months and exhibited no serious neurological lesions, but the majority died of meningitis or of associated hydrocephalus.

These early years of treatment of spina bifida were associated with poor prognosis, serious disabilities and inadequate means of therapy. The situation is graphically illustrated by Nash (1956). He describes the

> paraplegic incontinent cripple, who may be snatched from the jaws of death in the neonatal months, only to be delivered over to the tragedy of an expanding head, or to a life of social exclusion amid the fumes and filth of double incontinence and tropic ulcers. (p. 1334)

Reflecting on this situation, Smith (1965) observes:

> . . . it is not to be wondered that many clinicians should hope for an early demise in a child so afflicted. (p. 3)

(d) The years 1958–70 saw the development of the valve which made it possible to drain off the excessive amounts of cerebro-spinal fluid around or within the brain in presenting cases of associated hydrocephalus. The valve was developed by Holter, an American engineer, and used by Spitz on Holter's own child. This 'shunt' incorporated 2 undirectional valves which opened at a predetermined pressure. Since its early development, there have been many modifications in an attempt to overcome complications arising from its use.

With development of the shunt, and its potential for reducing intracranial pressure, it was expected that treated hydrocephalic children would develop with normal intelligence. This expectation led to enthusiasm to treat all spina bifida infants irrespective of the severity of their condition at birth. The problems created, however, were considered by some medical specialists to be worse than those solved:

> Treating all babies, without selection, resulted in such suffering for large numbers . . . The cost of medical care and of special education for each severely handicapped child exceeded £50 000 by the time they had reached 16 years of age. (Lorber 1976, p. 36)

(e) In the early 1970s, disheartening results from an analysis of the effects of surgery on 524 patients (Lorber 1971) were presented to the Society for Research in Hydrocephalus and Spina Bifida, in Freiburg. At this meeting, an attempt was made to find suitable criteria for selective treatment. The aim of non-selection for surgical intervention was avoidance of, or delay in, surgical treatment of infants exhibiting characteristics associated with severe handicap.

The need to select infants with this condition for surgical intervention remains a difficult aspect of treatment. Further discussion on this point is included later in the chapter (page 14). However, the increasing numbers of children who survive as a result of surgical intervention, and their evident ability to cope with many aspects of social interaction, including educational experiences, suggest considerable progress in treatment over the last decade.

2.1.2 Incidence

From the literature, the incidence of spina bifida and hydrocephalus, as distinct from other neural tube defects, is not always readily distinguishable. However, figures have been presented on the incidence of neural tube malformations, and include the conditions encephalocele and anencephalocele. Anencephaly is another condition in this group; it results from a virtual lack of development of the brain, only the brain stem being present.

The incidence of spina bifida varies in different parts of the world. Table 2.1, from Laurence (1969), shows a range from 0.3 to 4.1 per 1000 live births. The still-birth rate for spina bifida is about 24 per cent.

Anderson & Spain (1977) quote the incidence of anencephaly in Britain as 2 per 1000 total births and of spina bifida as 2.4 per 1000. The British Isles records some of the highest rates of neural tube malformations in the world, and there are striking regional variations in that country. Scotland registered 2.4 per 1000 (spina bifida) and 2.78 per 1000 (anencephaly) at the Glasgow Congenital Malformation Registry during the year 1972–73 (Hagard, Carter & Milne 1976). Scotland, Ireland and Wales are the areas of highest incidence in the British Isles. Hare, Laurence, Payne & Rawnsley (1966) quote 8.1 per 1000 in South Wales for all central nervous system (CNS) malformations. East Anglia and the south-east areas of Britain have the lowest incidence rates. However, Williamson (1965) reports an incidence of 6.04 per 1000 for all CNS malformations in the Southampton district for 4 years between 1958 and 1962, excluding 1959.

In summary, these broad findings suggest that anencephaly and its variants, including spina bifida cystica, have an incidence rate of about 5 per 1000 births. Within the British Isles the incidence varies considerably, with the fewest such births being recorded in East Anglia and the Home Counties, and the populations of highest risk being in South Wales, Scotland, Ireland and Merseyside. In general, South Wales has an incidence of over 7 births per 1000.

Lorber (1974) makes the following statements about the incidence of spina bifida:

> Spina bifida is one of the commonest and most important deformities with which a baby can be born. It is a condition which is visible immediately the baby is born and the diagnosis is not difficult.
>
> Spina bifida is almost as common in boys as in girls, but encephalocele is much commoner in girls — in a proportion of about 7 to 3.
>
> The number of babies born with spina bifida has been remarkably constant up till recently. In Great Britain, about 2 babies out of every 1000 born suffered from this malformation, but about 1 out of 4 are stillborn or died very soon after birth. This means that about 2000 such babies were born each year and some 1500 were alive at birth. It is commoner in Irish and Welsh populations. In a city of about half a million there will be about 20 such births a year. Although this is a large number, it is still a rare experience in the practice of a family doctor, who may not have more than one case in his practice in 20 years. This incidence partly explains why the public knows so little about the condition and why so few parents have ever heard of it until they have a spina bifida child of their own. Another reason for the public's ignorance is the fact that until recently most such babies only lived for a few weeks and often spent those weeks in hospitals. Often their parents never even saw them and it is probable that they were not told what the trouble was. Now the situation has radically changed. Large numbers of children are treated at special centres and large numbers survive to reach school age. (p. 5)

The survival rate is quoted by Anderson & Spain (1977) as 47 per cent of all spina bifida births for the first year of life. Of these, 87 per cent survive for at least 6 years. Anderson & Spain also refer to variations in seasons in which spina bifida births occur, the rates being higher than average in winter and lower than average in summer.

These British incidence rates are much higher than Australian figures. For example, Field (1972) quotes 1970 rates for New South Wales, when the incidence was determined at 2.2 per 1000 births for all central nervous system malformations — anencephaly, meningomyelocele and encephalocele. In Field's study, 713 cases of spina bifida were included. It was also reported that slight variations in incidence occur from year to year, and that there are seasonal peaks.[1] Carney (1971) estimated the incidence of spina bifida cystica in South Australia at about 0.8 per 1000 live births. An approximate incidence figure for Australia is 2 per 1000 when spina bifida and anencephaly are combined.

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[1] Williamson (1965) also examined seasonal variations in his Southampton study and concluded that there was no significant seasonal difference for spina bifida births, but that more anencephalic births occurred during the first quarter of the year (January–March).

Table 2.1: **Incidence of neural tube malformations in various research studies: per 1000 births**

	South Wales (Laurence et al. 1958a, b)	*Liverpool (Smith et al. 1967)*	*Belfast (Stevenson & Warnak 1959)*	*Southampton (Williamson 1965)*	*Birmingham (McKeown & Record 1960)*	*Charleston (Alten 1962)*		*Alexandria(a) (Stevenson et al. 1966)*	*Japan (Neel 1958)*
						White	*Negro*		
Anencephaly	3.5	3.1	4.6	1.9	2.0	1.2	0.2	3.6	0.6
Spina bifida	4.1	3.7	2.2	3.2	2.8	1.5	0.6	2.0	0.3
Hydrocephalus	0.5	0.5	1.5	0.9	1.9	0.8	1.1	2.0	0.3
	8.1	7.3	8.3	6.0	6.0	3.5	1.9	7.6	1.2

Source: K.M. Laurence, 'The recurrence risk in spina bifida cystica and anencephaly', *Developmental Medicine and Child Neurology*, Supp. 20, 1969, pp. 23–9.
(*a*) Not a population study.

2.2 MEDICAL ASPECTS OF SPINA BIFIDA AND HYDROCEPHALUS

2.2.1 Aetiology

The aetiology of spina bifida appears to be multifactorial, with significant genetic and environmental components (Carter, Laurence & David 1967). The genetic component is thought to be polygenic, but the mechanism by which it acts is unknown. The actual environmental component is also unknown. It may or may not be the result of specific action upon the susceptible embryo at around the 28th day of pregnancy.

Several authors recently have suggested a correlation of the incidence of spina bifida with various dietary factors (Knox 1972; Renwick 1972). Smith (1965) studied 192 families to whom a spina bifida child had been born, and states that no exogenous influence through the mother could be held suspect, such as early toxaemia of pregnancy, X-ray radiation, drug ingestion or other diseases, trauma, emotional tension or nutritional state. He states that 'the more significant finding . . . was the completely normal and uneventual course of the majority of pregnancies' (p. 13), and that the parents appeared to belong to all levels of society, and no economic environmental influence could be determined. These findings are in general agreement with others in the literature (see, for example, Record & McKeown 1949; Coffey & Jessop 1955). In 15 (7.8%) of the 192 families studied by Smith, more than 1 child in the same family was born with spina bifida cystica and 5 more families (2.6%) possessed a family history of the condition in a close relative (Table 2.2). Laurence & Roberts (1977) have suggested miscarriages are a manifestation rather than a cause of anencephaly and spina bifida.

Coffey & Jessop (1955) report that amongst 12 552 families, the familial incidence in all central nervous system anomalies, including spina bifida, was four times commoner than in a control group. Record and McKeown (1949) report that of 470 siblings born after the first malformed child, 2.8 per cent carried a nervous system defect.

Table 2.2: **Recurrence of spina bifida cystica in 192 affected families**

Recurrence	*Number*	*Per cent*
In a 2nd sibling	15	7.8
In a near relative	5	2.6

Source: E.D. Smith, *Spina bifida and the total care of spinal myelomeningocele*, Springfield, Illinois: Thomas, 1965.

2.2.2. Embryology

Spina bifida is thought to occur as a result of disturbances in embryonic development of the neural tubes. The exact form the malformation takes depends upon the exact time of

> action by the teratogenic insult . . . These disturbances in embryonic development are presumably the result of abnormal DNA patterns operating through 'messenger RNA' upon cellular metabolism and development . . . when acting in relationship to anterior neuropore closure, anencephaly will occur, and the various degrees of myeloschisis and the lesions associated with spina bifida will occur if the teratogenic action is just before or around the time of posterior neuropore closure. (Brocklehurst 1976, p. 21)

2.2.3 Genetic counselling

At present, little can be done about identifying the individual with genetic predisposition to development of spina bifida, because actual environmental factors thought to trigger off the malformations have yet to be identified. As a consequence, genetic counselling is rendered impotent in this area. The only method of prevention therefore lies in early antenatal diagnosis followed by selective termination of the pregnancy, if this is desired (Carter 1974).

Antenatal diagnosis

In 1972, Brock and Sutcliffe, working in Edinburgh, discovered that alphafetoprotein is present in excessive quantities in the amniotic fluid if the foetus has anencephaly or 'open' spina bifida. Through amniocentesis, a procedure in which the uterine wall is penetrated allowing some amniotic fluid to be drawn off, the alphafetoprotein level in the amniotic fluid can be estimated. The procedure is carried out during the 16th to 18th weeks of pregnancy. Unfortunately the procedure tends to be available only in larger cities where specialised laboratory facilities are found. More recent research has tested the usefulness of betalipoprotein in early pre-natal diagnosis (Brock 1976).

The aim of the procedure is the screening of 'at risk' pregnancies in mothers with a family history of neural tube malformation, and a reduction in the incidence of neural tube defects as a result of terminating affected pregnancies. However, the Australian experience is associated with a number of false positives, which has dampened enthusiasm for this test.[2]

A more valid assessment of the usefulness of amniocentesis in the diagnosis of spina bifida will probably become possible as further experience in its use is gained. Antenatal detection and selective termination of those pregnancies at 'high risk' of neural tube malformation (Scrimgeour 1978) would, however, reduce incidence by only a small number, for 90 per cent of cases are born to mothers who have no family history of neural tube malformation (Laurence 1976).

Table 2.3: **Risk of neural tube malformation**

Risk situation	*Approximate risk*
Whole population	1:200
One previous affected child	1:20
Two previous affected children	1:10
One parent affected	1:25
One aunt or uncle affected	1:50
One cousin or great-aunt or great-uncle affected	1:100
Other relatives affected	1:200

Source: K.M. Laurence, 'Genetic counselling and antenatal diagnosis for parents who have produced an infant with spina bifida', in T.E. Oppe and F.P. Woodford, *Early management of handicapping disorders*, IRMMH Review of Research and Practice, 1976, p. 62.

Recurrence risk

When parents produce a child with one of these malformations, the risk of a subsequent pregnancy ending similarly is about 1 in 20 (Table 2.3). The risk increases to more than 1 in 10 if the parents had 2 such pregnancies (Carter & Roberts 1967). A study of adult survivors with spina bifida, some of them severely affected, suggests that they run a risk of about 1 in 25 of producing an affected child

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[2] See, for example, *Australian Journal of Mental Retardation*, 5(2), 1978, p. 58.

(Laurence & Beresford 1975). There seems to be no evidence of variance in the sex ratio among affected children (James 1979a) nor of a dominant sex among the children of spina-bifida-prone mothers (James 1979b). Neither maternal nor foetal factors appear to dominate in the results of recurrence studies (Lalouel, Moreton & Jackson 1979).

2.2.4 Classification of disorders

Spinal disorders

The literature abounds in a variety of terms which relate to these disorders, with resulting confusion in the interpretation and comparison of findings. The condition generically known as spina bifida, however, may be subdivided into the following:[3]

(a) *Spina bifida occulta* is the unfused condition of vertebral arches without any distension of meninges. There may or may not be changes in the overlying skin, neurological signs or pathological changes in the spinal cord.

(b) *Meningocele* is the unfused condition of vertebral arches with cystic distension of the meninges, but absence of myelodysplasia of the spinal cord and absence of neurological signs. Parts of the cord or nerve roots may or may not be present in the sac of meninges, but if present, they conduct impulses normally.

(c) *Myelomeningocele*, or *meningomyelocele*, is the unfused condition of vertebral arches with distension of the meninges and is associated with myleodysplasia of the spinal cord and neurological signs.

Within this 3rd group all pathological variations in the structure of the cord may be included, for instance myelocele, myelocystocele, hydromyelia or myeloschisis.

Groups (b) and (c) are conveniently grouped under the term 'spina bifida cystica', although the prognosis of the 2 groups is vastly different.

Intracranial disorders and malformations

As well as the defining malformations of the spinal column, spina bifida is often accompanied by abnormalities of brain development which, if they block the drainage of cerebro-spinal fluid, may cause hydrocephalus:

(a) *Arnold Chiari malformation* occurs to some degree in most cases of spina bifida. It consists of a tongue-like projection of the cerebellum down into the cervical canal. The condition is associated with elongation of the medulla oblongata and displacement of the 4th ventricle. The cervical spinal cord is also displayed downwards.

(b) *Hydrocephalus* is an important complication which may be present at birth, or occur soon afterwards, in over 80 per cent of babies born with spina bifida (Lorber 1961). Hydrocephalus is caused by an obstruction to the normal flow of cerebro-spinal fluid (CSF), due to the distorting effect of the Arnold Chiari malformation as it occupies the foramen magnum and displaces the foramina of the 4th ventricle into the spinal canal. Cerebro-spinal fluid is constantly in circulation under varying degrees of pressure and is absorbed on the surface of the brain. Arnold Chiari malformation causes an increase in intravesicle pressure, and results in dilation of the ventricles and increased intracranial pressure. The Aqueduct of Sylvius is commonly implicated in this respect. The lesion may take 1 of 2 forms: firstly as a simple stenosis where the calibre is diminished; or, secondly, where forking or atresia occurs which can cause functional blocking. These factors contribute to hydrocephalus, which becomes more apparent after birth, with rapid enlargement of the head. This enlargement is associated with a thinning of the cerebral cortex.

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[3] It will be noted that Tew (1973) presents a classification, outlined in Chapter 1, which includes encephalocele as a 4th type of spina bifida.

Spontaneous arrest of hydrocephalus may occur. Flexner (1933) showed that secretory activity of the cheroid plexus (where CSF is produced) reduced as intraventricular pressure increased. This factor, when coupled with transventricular absorption, may bring about an arrest. However, the nature of spontaneous arrest still remains to be completely defined (Brocklehurst 1976).

Complications commonly associated with spina bifida

(a) *Meningitis* (infection of the meninges) is an ever-present risk with any lesion completely covered by skin. Once meningitis is established, the infant is extremely resistant to treatment and the prognosis is very grave. Smith (1965) states that of a series of 59 patients who developed meningitis, some 52 died. Lorber & Segall (1962) have reported a figure of 80 per cent of patients not surviving after contracting meningitis.

Should a child survive a meningitis attack, adhesion formations are said to occur in the subarachnoid space, further complicating the hydrocephalus and aggravating existent neurological damage.

(b) *Incontinence* is one of the main problems in children with spina bifida, and involves lack of bladder and bowel control. Most children have incontinence reduced to manageable proportions by means of combining self-regulating habits and/or reliance on aids and prostheses. Reaching a stage of control is often associated with considerable experimentation and expense (a detailed account of these procedures is outlined later in this report: see page 163).

(c) *Sensory loss* may also be present. An accurate assessment of sensory loss cannot be made until the child is at least 6 years old. In a number of cases, crying in response to pinprick or skin stimulation during electrical testing may give a rough estimate of sensory level. However, movement of the limb in response to stimulation of the skin, unaccompanied by a general arousal of the child, is more likely to be a reflex response than a voluntary action.

Sharrard (1976) states that when sensitivity can be more accurately assessed, it is often found that the areas of normal sensory supply correspond with the level of motor innervation, and that it is always advisable to assume that areas supplied by the sacral neural segments (particularly the perineum and the feet) are insensitive and therefore liable to pressure ulceration (see Figure 2.1).

The more active the child, the greater the likelihood that pressure sores will develop in areas of anaesthetic skin. Parents and teachers need to look for areas of excessive redness caused by rubbing of boots, plastic casts or calipers on skin surfaces incapable of registering the normal warning of pain or discomfort.

(d) *Spontaneous fractures* are liable to occur with spina bifida children in bones of the lower limbs (James 1970), and there is a relationship between the most likely site of these pathological fractures and the level of the lesion of the spine. In limbs with complete paralysis, fractures may occur at any part of the femur or tibia. If there is innervation down to the 3rd lumbar level, the commonest site of fracture is the lower end of the femur or upper tibia. If innervation exists to the 5th lumbar level, the fracture is more likely to occur at the lower end of the tibia or in the foot. There may also be metabolic causes for bone fragility, such as renal rickets, due to disturbance of vitamin D metabolism or abnormal utilisation of vitamin C, which can cause epiphyseal displacements (McKibbin & Porter 1967).

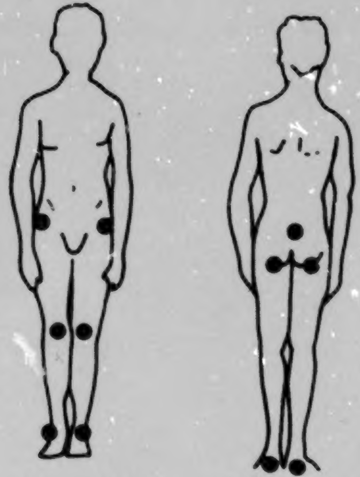

Figure 2.1: **Areas prone to pressure sores** (Source: *Spina bifida: a handbook for parents,* Spina Bifida Association of South Australia, 1974)

2.2.5 Treatment

Selection for treatment of spina bifida

Since the early 1970s, there has been a change in the climate of opinion, away from routine operative treatment in all cases of spina bifida. In 1971, Lorber presented his crucial analysis of treatment results (see page 7), in which he evaluated the later results of early surgery and drew attention to the high incidence of grave disability among children in Sheffield, where most were receiving active therapy. In this 1971 article, Lorber implied that it may be wiser to abandon immediate repair as a routine for all children with spina bifida, leaving the most severely affected children unrepaired, while continuing immediate repair and further energetic treatment for the less severely affected children.

This approach differed markedly from one that suggested operating on all affected infants, even if it was certain that many survivors would suffer from multiple handicaps (Zachary 1966), which itself may be a source of anxiety to those who consider it wrong to treat infants whose predictable quality of life would be poor. Rickham & Mawdsley (1966) stated that mere saving of life was not enough unless the lives were worth saving, while Eckstein & Macnab (1966) opposed immediate selection in the newborn, suggesting that judicial selection be undertaken later, when the child experiences some life-threatening problem such as infection.

It therefore appears that in spite of the best technical advances, and the most humane attempts at treating infants with spina bifida, there is no really satisfactory or absolute approach to treatment. 'The best hope for the future lies in prevention of conception of such infants, but we are far from that' (Lorber 1974, p. 307). In the meantime, selection for treatment offers the possibility of comprehensive care for the babies who, it is believed, can truly benefit.

The following criteria for non-selection for treatment have been put forward. Any one of the following signs indicates that survival will be accompanied by severe disability (Lorber 1974):

(a) Gross paralysis of legs — paralysis below 3rd lumbar vertebral level with, at most, hip flexors, adductors and quadriceps being active;
(b) Thoracolumbar — thoracolumbosacral lesion related to the vertebral level;
(c) Scoliosis or kyphosis clinically evident at birth;
(d) Grossly enlarged head with maximal circumference of 2 cm or more above the 90th percentile related to birth weight;
(e) Intracranial birth injury;
(f) Other gross congenital defects.

Each infant's social condition is also considered in detail as part of the selection procedure. In addition to the above criteria, it has been suggested that no active treatment be undertaken for those children who, after closure, develop meningitis or ventriculitis, and who already have serious neurological handicap and hydrocephalus. It is also suggested that no active treatment be undertaken should the child be exposed to a life-threatening episode (Lorber 1974). These criteria are almost identical to the criteria proposed by Smith & Smith (1973) and Stark & Drummond (1972).

However, as Lorber suggests, a policy of selection does not solve the problem of a child not receiving surgery surviving with severe disabilities. Though most do not survive, not all children who are not operated on die[4], and these children are therefore left more severely disabled than may have been necessary given surgical intervention at an earlier stage. In choosing not to treat a child, without assuring non-survival and without preventing additional defects resulting from non-treatment, we have incurred the worst possible outcome (Freeman 1974). The debate on whether selection is the correct procedure, or whether every child should be treated, continues (Lorber 1978; Zachary 1978), as does research into the reliability of predictions on the outcomes of spina bifida (Laurence, Evans, Weeks, Thomas, Frazer & Tew 1976).

Clearly, those concerned in making the decision about surgical intervention, especially the medical specialists and parents, are faced with ethical and emotional situations of considerable difficulty (Habgood 1975). Decisions about surgery associated with spina bifida tend to be made within hours of birth, coming at a time when the parents are in a most vulnerable emotional state. The impact on them is considerable. The complexity of the medical problems and the accompanying feelings of grief, guilt and inadequacy are likely to render them temporarily unable to cope. For some families a disability is a challenge that is met by the individual's resolve to overcome, and the family's united effort to see that the disabled child does succeed (Ellis 1974). For others, severe disability presents an insurmountable barrier, preventing acceptance of the child and the disabilities.

Most writers suggest that it is the duty of the medical specialist to make the decision about surgery. Ellis (1974) points out that he or she should be a consultant and an expert in this field of medicine, but further suggests that 'joint consultation' (that is, with parents and grandparents included in discussions) be attempted rather than leaving the specialist to act as both adviser and sole adjudicator.

When examination of the infant and discussions with the family lead to the conclusion that surgery is inadvisable, custodial care only is recommended (Lorber 1971). This method of treatment involves nursing the neonate in a cot with the lesion either exposed or covered with a light dressing. The infant is demand fed, and irritability treated with sedation, but antibiotic therapy is withheld. For these patients, and their families, it is the specialists' and community's responsibility to provide this care and to minimise suffering and to ensure ongoing supportive contact if and when the infant is cared for at home.

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[4] Most severe cases, if not operated on, rarely survive long, some 90 per cent dying within the infant's 1st year of life (Hide, Williams & Ellis 1972; Smith & Smith 1973).

Where treatment is undertaken, surgical closure is carried out under general anaesthetic. Closure consists of isolating the neural tissue and identifying its continuity with the spinal cord and nerve roots. This vital tissue is preserved. Around it is secured a layer of tissue producing a cover for the plaque and nerve roots. This cover is called a 'dural sac', because it is continuous with the dura around the spinal cord on the rostral sides of the lesion. Finally, the layer of skin, which has been undermined in all directions, is drawn across the wound and sutured.

Management of hydrocephalus in spina bifida

Various attempts have been made in recent years to treat infants with progressive hydrocephalus by medical, as opposed to surgical, means.

In 1967, Hayden and Shurtleff reported on a series of trials using isosorbide, an osmotic agent which acts by reducing intracranial pressure associated with hydrocephalus. Later, in 1972, Lorber published his results of similar trials using isosorbide therapy. From these analyses it would appear that this drug is of limited value as a form of treatment for hydrocephalus, particularly in severe cases. It has not formed part of the treatment regime in Queensland.

Surgical treatment of hydrocephalus, especially in selected cases of progressive hydrocephalus, is the more usual management method. Insertion of a ventriculo-atrial, or ventriculo-peritoneal shunt, using one of a range of available valves, is the more common approach to surgical treatment of the problem.

The Pudenz–Heyer and Spitz–Holter valves tend to be used in the neonate, even though blockage of the lower ends of such a shunt by the time the infant is 9 months of age is almost inevitable as a result of the child's normal growth displacing the catheter (Brocklehurst 1976). Eckstein & Macnab (1966) state that the advantage of using a ventriculo-atrial shunt early is that the head size remains normal and the cortical thinning is notably reduced.

Both the Pudenz–Heyer and the Spitz–Holter shunts have a ventricular catheter which is inserted, through a burr-hole, under a flap of scalp in the right posterior temporal area; 4 cm of the catheter lies along the body of the lateral ventricle. The Pudenz–Heyer shunt has a reservoir which sits in the burr-hole and is accessible for diagnosis and therapy when necessary. The cardiac catheter is passed down the internal jugular vein. The right side of the head is used because the course of the right internal jugular vein down to the innominate vein and superior vena cava is more direct than the course of the left internal jugular vein. The Pudenz–Heyer shunt has a non-return at the atrium, whereas the Spitz–Holter valve lies subcutaneously near the burr-hole site (see Figure 2.2).

The insertion of a shunt to ameliorate the effects of hydrocephalus has introduced a whole group of secondary problems. Possible shunt complications are various and frequent, and may include such problems as infection (Morrice & Young 1975), detachment or blockage, each with severe implications for the patient. Lengthening of the shunt tubing is often appropriate as the child grows.

Management of bladder and bowel in spina bifida

Care of the bladder Brocklehurst (1976) states that the urinary tract and bowel are involved in 90 per cent of spina bifida cystica cases and in a significant number of cases where the spinal defect is less obvious. Their management is an important part of the total care of spina bifida. Proper urological management has much to offer these children by avoidance of chronic ill health and social ostracism.

Urinary tract problems may not be readily detected at birth. A spina bifida infant with an efficient reflux bladder may appear to perform normally until the age is reached when voluntary control should be attained. It then becomes increasingly obvious that the child lacks normal sensation of a full bladder and cannot consciously stop or start the urinary flow.

Inefficient bladder emptying is thought to be responsible for almost the whole range of conditions associated with progressive deterioration in the urinary tract. Incomplete emptying, with residual urine of more than about 30 mL, makes recurrent infection inevitable (Brocklehurst 1976). Quite apart from anatomical or functional abnormalities of the renal tract, spina bifida children are more susceptible to urinary infection than are non-disabled children. Lorber, Meneer & Allott (1968) found 50 per cent of all spina bifida infants to have infected urine before their 1st

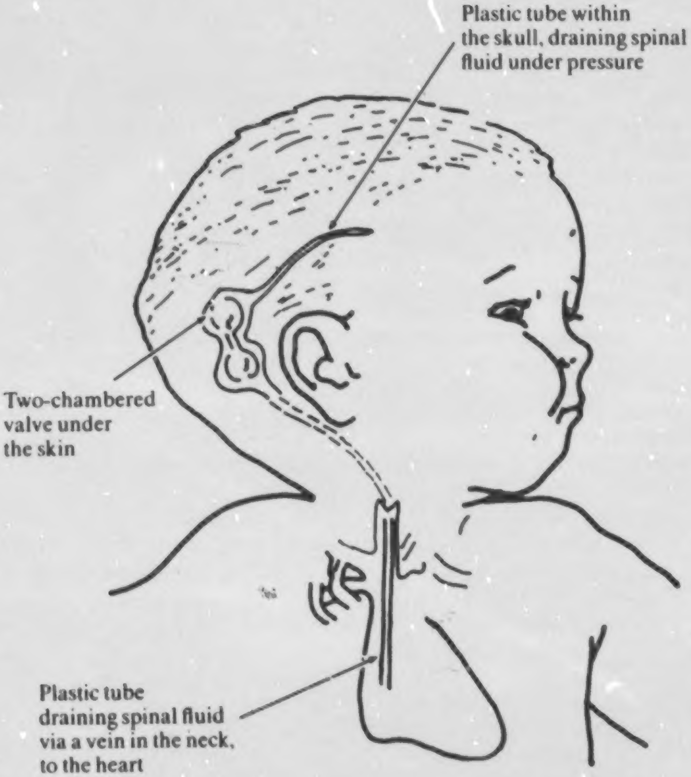

Plastic tube within
the skull, draining spinal
fluid under pressure
Two-chambered
valve under
the skin
Plastic tube
draining spinal fluid
via a vein in the neck,
to the heart

Figure 2.2: **Inserting shunt in cases of hydrocephalus** (Source: *Spina bifida: a handbook for parents*, Spina Bifida Association of South Australia, 1974)

birthday. Only about 25 per cent of all cases never develop infections. These authors note that sterilisation of urine can be achieved by use of strong antibiotics, but also note that infection recurs after completion of a course, resulting from persistence of pockets in damaged renal parenchyma (see also Cass 1976; Drago, Wellner, Sanford & Rohner 1977; Mulcahy, James & McRoberts 1977).

The effect of dilatation and elongation of ureters, combined with infection, results in renal cortex thinning and hydronephrosis. These complications may result in renal failure and death. However, few young patients die from renal failure, although a proportion of adult spina bifida patients do. In an attempt to reduce this probability of deterioration, many procedures are undertaken to maintain free drainage of urine, for 'once dilatation and tortuosity of the upper tract become severe, not even supra-vesical diversion will permit a return to normal' (Forrest 1976, p. 128).

Forrest has summarised the major aspects of management of renal problems as follows:

(a) Maintenance of renal function and prevention of infection are prompted by the intake of copious fluids. Encouraging a young child to develop a good fluid intake pattern is an essential aspect of health maintenance.

(b) Manual expression (often referred to, if incorrectly, as Crede manoeuvre), in which pressure is applied to the lower abdomen in an attempt to express urine from the bladder. About 40 per cent of cases have an expressible bladder, although residual urine is thought to provide a source of infection.

(c) Cholinergic drugs are prescribed for patients in whom manual expression leaves an unacceptably large residual volume of urine.

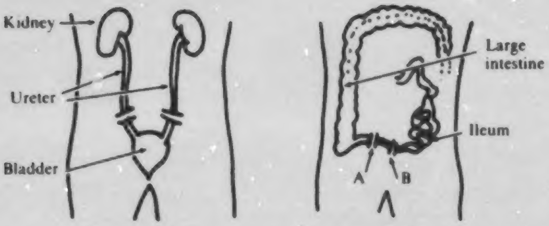
(d) Surgical procedures have been designed to control outflow obstruction (occurring at the bladder neck or external sphincter), or to prevent reflux of urine (at the level of the ureters). Mogg (1967) states that the ileal or colonic loop is the most effective form of permanent drainage for a neuropathic urinary tract, particularly in females. Conversely, Brocklehurst (1976) states that evidence is mounting that diversion can still cause dilatation in a previously normal upper renal tract.

    The ileal or colonic loop procedure is usually undertaken when a child is about 2 years old. As a result of the surgery, the ureters are disconnected from the bladder and brought to the surface of the abdomen. If the ureters are too short, a segment of ileum is stitched to the ureters and the other end brought out onto the abdominal wall. Urine is then passed from the kidneys, down the ureters, into the ileal segment and through the stoma, where it is collected in a bag (Figure 2.3).

(e) Penile appliances for males, consisting of a rubber or plastic collecting bag, are relatively successful. There are many designs, but young children tend to use the pubic pressure urinal, while older boys tend to use the penile spout urinal (Figure 2.4).

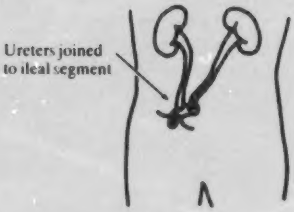
(f) Electronic methods using electrodes and electronic circuits have also been tried with varying degrees of success.

(g) Intermittent catheterisation is used to relieve acute retention. Non-sterile, intermittent self-catheterisation is the most recently introduced method of attaining continence. Lapides, Diokno, Lowe & Kalish (1974, p.184) postulate the theory that 'over-distension of the bladder causes ischaemia of bladder tissues which are then prey to invading gram-negative organisms from the patient's own gut'. They therefore suggest that if patients with a neurogenic bladder regularly catheterise themselves in a non-sterile manner, using an unsterile catheter, continence is achieved and urinary infection avoided.


Kidney
Ureter
Bladder
Large intestine
Ileum
A
B

Ureters divided near the bladder

A segment of ileum is removed and used to form the conduit
The severed ileal (A, B) is rejoined


Ureters joined to ileal segment

The end of ileal conduit on the skin above the abdomen: the stoma

Figure 2.3: **Ileal conduit** (Source: *Spina bifida: a handbook for parents,* Spina Bifida Association of South Australia, 1974)

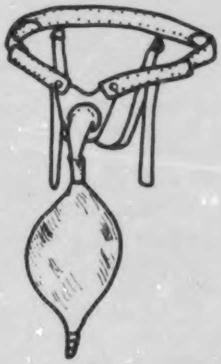


Figure 2.4: **The 'Chailey' male urinal** (Source: *Spina bifida: a handbook for parents,* Spina Bifida Association of South Australia, 1974)

Care of the bowel Most spina bifida children will have paralysis of the external anal sphincter. Although the medical consequences may be much less serious than the effects of a paralysed bladder, this aspect may present to the child and family involved as the most troublesome aspect of the condition of spina bifida.

It is important to try to establish a regular bowel habit from infancy and to avoid any gross overloading that could destroy any remaining stretch reflux. Attention to diet and a combination of abdominal pressure, manual expression and careful use of aperients may all contribute to bringing about some semblance of bowel 'control'.

A minority of patients have lax sphincters. This usually makes control impossible and may prevent social integration of the child. Again, regulation of diet and prescription of combined measures and laxatives may be effective. Some individuals resort to a permanent colostomy as a means of control, while for others attempts are being made to improve sphincter tones by means of electrical stimulation (Brocklehurst 1976).

Orthopaedic management

In the first 2–3 years of life, orthopaedic management is mainly prophylactic in nature, and is largely concerned with preventing flexure contractures and setting the conditions for feet to be weight-bearing, without developing pressure sores.

The most common cause of orthopaedic deformity in spina bifida is the phenomenon of unbalanced muscle action. As a result of nerve damage associated with spinal lesion, muscles producing an action at a joint will be rendered paralysed. The unopposed muscle action produces progressive deformity because of its mechanical advantage over its weak opponent (Sharrard 1962).

Bony deformities may also develop when an unopposed muscle does not lengthen as fast as bone, because of lack of stimulation from its opponent (Sharrard 1967). The paralysed muscle on the opposite side of the deformity becomes progressively lengthened, but paralysed muscles on the same side as the deformity will shorten. Deformities which develop *in utero* affect all the limb structures, including the skin, which results in a child having a rigid limb. Sharrard (1976) states that deformities due to muscle imbalance are not correctable by passive movement or splinting, and that if improvement is temporarily regained, the deformity recurs on removal of the splints.

The aim of orthopaedic treatment of the spina bifida child is the correction of the deformities in sequence until the limbs approach normal functioning to an extent sufficient to allow walking, or the fitting of calipers which will at least enable a child to be weight-bearing and, hopefully, capable of learning to walk (see Table 2.4). Orthopaedic treatment must be integrated with other specialist treatment. In general, measures relating to neurosurgical or urological problems take priority over orthopaedic measures (Menelaus 1971).

Sharrard (1976, p. 92) has listed some basic principles which apply to treatment of the lower limbs:

(a) Conservative, corrective treatment is contra-indicated when there are allied problems of anaesthetic skin and associated pressure sores.
(b) Deformity should be corrected by elongation of the short tendons, muscles and associated soft tissues. Provided this is done before the age of 3 or 4 years, it is often possible to correct even severe deformities without resort to surgery upon bone.
(c) Various surgical procedures have been designed to establish muscle balance by means of transfer or lengthening of the tendons.

Table 2.4: **Predictable activity in myelomeningocele**

Class (Sharrard)	*Motor level spinal cord segment*	*Critical motor function present*	*Mobility–activity range*		
			School-age	*Adolescent*	*Adult*
I	T–12 (12th thoracic)	Totally paralysed lower limbs	Standing brace Wheelchair	Wheelchair	Wheelchair No ambulation
II	L–1–2 (1st and 2nd lumbar)	Hip flexor muscles	Crutches Braces Wheelchair	Wheelchair Household ambulation	Wheelchair Non-functional ambulation
III	L–3–4 (3rd and 4th lumbar)	Quadriceps muscles	Crutches Braces Household ambulation Wheelchair	Crutches Household ambulation Wheelchair	50% wheelchair Household ambulation with crutches
IV	L–5 (5th lumbar)	Medial hamstrings Anterior tibial muscles	Crutches Braces Community ambulation	Crutches Community ambulation	Community ambulation with crutches
V	S–1 (1st sacral)	Lateral hamstring and peroneal muscles	Community ambulation	Community ambulation	Community ambulation; 50% crutch or cane
VI	S–2–3 (2nd and 3rd sacral)	Mildness of instrinsic foot muscles possible	Normal	Normal	Limited endurance due to late foot deformities

Source: E. Bleck & D.A. Nagel (eds), *Physically handicapped children — a medical atlas for teachers*, New York: Grune & Stratton, 1975, p. 190.

(d) Immobilisation after surgery should continue for the minimum time necessary to allow healing of the soft tissue. This need rarely last longer than 4 weeks.

(e) Correction of deformity involving bone surgery tends not to be undertaken unless correction using soft tissue has failed.

(f) When deformity has been corrected at all joints, one can begin a planned program to promote ability to walk with the aid of suitable appliances. The program will involve calipers, walking aids and physiotherapy.

A comprehensive discussion of orthopaedic management, and of physiotherapy assessment and treatment related to such management, is included in Chapter 3 of this report.

2.3 PSYCHO-EDUCATIONAL ASPECTS OF SPINA BIFIDA AND HYDROCEPHALUS

Description of the psycho-educational characteristics of children with spina bifida and hydrocephalus is complex because of the diversity of type and severity of disorder which may be found. This section of the review looks at three basic areas:

(a) psychological and related developmental characteristics
(b) school placement
(c) school achievement

Within each of these, specific aspects of the topic have been included. A chronological discussion has been used in presenting the information to give a basis for comparison between areas. It will be noted that some studies have looked at a wide range of psychological and educational characteristics of these children; others have limited their investigation to a few particular characteristics.

2.3.1 Psychological and related developmental characteristics

There are not many studies which report on the intellectual characteristics of spina bifida children, and most of these have been reported within the last 10 years. Some additional investigations have looked at the effects of hydrocephalus on intellect.[5]

Range and distribution of intelligence test scores

Burns (1967) examined 70 children with meningomyelocele and encephalocele using the Stanford–Binet (LM) (Terman & Merrill 1961) and Merrill–Palmer (Stutsman 1948) scales and found that measured intelligence ranged from I.Q. 20 to I.Q. 148. One-tenth displayed I.Q. scores less than 50, while approximately half (54%) of the group fell into the I.Q. 50–I.Q. 90 range. A little more than one-third (38%) had I.Q. scores greater than 90.

Spain (1970), in a study of 161 children with encephalocele and spina bifida seen at about 1 year of age, reported a broad spread of test scores even at that early age. Developmental quotients from the Griffiths Scale (Griffiths 1954) ranged from less than 50 (6% of cases) through to the average I.Q. band (26% of cases) when measured on all subscales. Most children (68%) fell in the below-average range. The majority of scores were depressed by the children's results in the locomotor area.

A small study by Scherzer & Gardner (1971), of 14 children with meningocele, records intelligence quotients on the Wechsler Intelligence Scale for Children

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[5] In some of the following sections it has been found useful to review studies dealing with the psycho-educational characteristics of children experiencing only hydrocephalus. Whenever possible, the specific diagnosis of the subjects is stated.

(WISC) (Wechsler 1949) ranging from 55 to 118 on the verbal scale and between 47 and 113 on the performance scale. The full-scale I.Q. scores showed a range of 46–117. Twenty-nine per cent of the sample scored less than I.Q. 50; 29 per cent also scored in the 50–85 I.Q. range; and 42 per cent had scores greater than 85.

Intelligence test scores and type of spina bifida

Laurence & Tew (1971) reported the results of Stanford–Binet and Griffiths Scale (Griffiths 1954) tests for groups of children with various diagnoses. Eight encephaloceles had a mean I.Q. of 56 (SD = 23), and 37 myeloceles recorded a mean I.Q. of 94 (SD = 18). While these results do not reflect 'normal' distributions, the meningocele population showed less skew and kurtosis than the most frequently occurring condition of myelocele or the less frequent but more severe condition of encephalocele.

In a later study, which generally used the same population as that reported above, Tew & Laurence (1972) present similar results on the Wechsler Intelligence Scale for Children. The results for the two studies are presented in Table 2.5.

Intelligence test scores and sex

Tew & Laurence (1972) report significant differences in mean intelligence test scores between boys and girls. The mean full-scale I.Q. on the WISC is reported at 93 for boys and 73 for girls. They are the only researchers to have reported this marked difference between intelligence test scores for this group.

The effects of hydrocephalus on the intelligence test scores of children with spina bifida

Badell-Ribera, Schulman & Paddock (1966) compared results from the WISC and Wechsler Adult Intelligence Scale (WAIS) (Wechsler 1955) for 47 subjects experiencing spina bifida with hydrocephalus, and 28 with spina bifida only. Both the hydrocephalic and non-hydrocephalic groups were also divided into two groups — (i) a less handicapped group and (ii) a more handicapped group — on the basis of degree of physical disability. In the more handicapped group the subjects with hydrocephalus had significantly lower verbal, performance and Full-Scale I.Q.s than those with spina bifida only.

Table 2.5: **Intelligence test results: by type of spina bifida**

				Tew & Laurence (1972)(b)				
	Laurence & Tew (1971)(a)				*Mean I.Q.s*			
Type of spina bifida	*No. of subjects*	*Mean I.Q.*	*SD*	*No. of subjects*	*Verbal*	*Perform.*	*Full Scale*	*SD*
Encephalocele	8	56	23	9	61	52	52	23
Myelocele	37	56	22	32	94	85	89	18
Meningocele	18	94	17	17	95	93	94	13

(*a*) On basis of Stanford–Binet.
(*b*) On basis of Wechsler Intelligence Scale for Children.

For the less handicapped group the mean performance I.Q. of the subjects with hydrocephalus was significantly lower than for the group without hydrocephalus. No statistically significant difference was found for Full-Scale I.Q. scores, but there was a tendency for the I.Q.s of the hydrocephalic subjects to be lower. The mean verbal

I.Q. for this less handicapped group showed no statistically significant difference between subjects with and without hydrocephalus.

Tew & Lawrence (1975b) used the presence or absence of a shunt in a group of 59 children as an indicator of the presence or absence of hydrocephalus. The group consisted of 46 myeloceles, 9 meningoceles, 2 encephaloceles and 2 congenital hydrocephalics. Thirty-one had surgically inserted shunts for the control of hydrocephalus. The group not displaying hydrocephalus, and therefore without shunts, had a mean Wechsler Preschool and Primary Scale of Intelligence (WPPSI) (Wechsler 1967) score of I.Q. 90, or 14 I.Q. points lower than the British mean I.Q. of 105. Tew & Laurence reported that the mean I.Q. of those with shunts was significantly lower than the mean I.Q. for those children without shunts.

The reports of Badell-Ribera et al. and Tew and Laurence provide evidence to show that the presence of hydrocephalus with spina bifida may have a further debilitating effect on intellectual development than in cases where hydrocephalus is not present (see also Raimondi & Soare 1974; Soare & Raimondi 1977; Tew 1977; Bottcher, Jacobsen, Gyldensted, Harmsen & Gloerselt-Tarp 1978).

The intellectual characteristics of children with hydrocephalus

Hydrocephalus occurs in the population apart from its association with spina bifida. A number of studies have looked at the intellectual growth of hydrocephalic children due to a number of causative conditions. It should be noted, however, that in some studies a significant proportion of the hydrocephalic group being considered also has spina bifida, although this may not always be the case. These studies of hydrocephalic children provide a broader base from which to view the effect of hydrocephalus on cognitive development, as it seems likely that the presence of hydrocephalus is a major factor in the development of psycho-educational characteristics.

Laurence & Coates (1962) studied 81 hydrocephalic children. The Stanford–Binet Test was administered to 40 of the group, the Merrill–Palmer Test to 10, and the Griffiths Scale to 18, while unnamed tests were administered to 4, and results estimated for 9 children. The average I.Q. for the group was 69, with a standard deviation of 31.

The negatively skewed distribution in the Laurence and Coates study is supported by reports from Hagberg & Sjorgen (1966). They examined 63 cases of naturally arrested hydrocephalus using a modified Stanford–Binet Test, and described the population as falling into three groups: (i) 37 per cent with I.Q. scores above 90 (n=23); (ii) 38 per cent with I.Q. scores 50–90 (n=24); and (iii) 25 per cent with I.Q. scores less than 50 (n=16).

The results of these surveys indicate that hydrocephalic children show a very different distribution of intelligence test scores from the non-handicapped population, adding support to the conclusion that hydrocephalus in spina bifida children is an additional debilitating condition.

Verbal and general language skills of spina bifida children

Since the mid–1960s, clinical observers have frequently reported two factors regarding the spina bifida child, and more particularly the spina bifida–hydrocephalic child. These are (i) a personality trait variously described by terms such as 'talkative' or 'chatterbox', and seen as an apparent ease with everyday conversational phrases but lacking conceptual depth, and (ii) an apparent difference between estimates of the verbal and performance skills of these children, with higher scores in the verbal area.

In a study by Badell-Ribera et al. (1966) of 75 cases of spina bifida (47 with spina bifida only), it was found that the hydrocephalic groups showed a significant discrepancy between verbal and performance scores on the WISC or WAIS, and the researchers concluded that the relatively high verbal scores with lower performance scores reflected what has been clinically described as the 'cocktail party syndrome'.

Parsons (1968) looked at four groups of subjects in an endeavour to find some basis for these clinical observations. The groups were:

(a) a group of children with hydrocephalus not associated with spina bifida (n = 9);
(b) a group with both spina bifida and hydrocephalus, and also exhibiting paraplegia and/or incontinence (n = 20);
(c) a spina-bifida-only group, also exhibiting paraplegia and/or incontinence (n = 20); and
(d) a control group of children hospitalised for other orthopaedically based disorders (n = 13).

Tests of vocabulary, morphology and short-term verbal memory were administered. No significant difference was found between the mean scores for the groups on any of these measures; thus support for the clinical observations could not be drawn.

Clinical observations of the type discussed above, however, continued to be reported. Basing their research in Wales, Laurence and Tew have reported on a number of occasions the presence of the 'cocktail party syndrome' in spina bifida populations. They report the phenomenon as more frequent among patients of below-average intelligence (Laurence & Tew 1971, p. 136) and later state that not less than 28 per cent of their sample of 58 subjects show varying signs of the syndrome. This group were all myeloceles or encephaloceles, and it was suggested that the presence of the 'cocktail party syndrome' is a certain indication of below-average, if not subnormal, intelligence (Tew & Laurence 1972). This finding was supported in later research (Tew 1979).

Spain (1970) examined 145 spina bifida children at 3 years of age on 2 scales from the Griffiths (1954) Test plus the Reynell Scales (Reynell 1969). In general, she found that children with shunts appeared to be developing normally in language areas. Severe physical handicaps were also found to be associated with the presence of a shunt, particularly in those children who had low scores on a performance-type intelligence test. Children with shunts who had below-average performance scores or language performance tended to have poor verbal scores, and 40 per cent of these children were rated as being hyperverbal. These children also showed a characteristic pattern for language expression, with good syntax and vocabulary scores but poor ability to use language expressively.

Verbal and general language skills of hydrocephalic children

The debate on the presence of hyperverbalism in the spina bifida population is marked by inconclusive and divergent research findings. However, it is clear that when the syndrome is reported, it is most frequent in those with spina bifida and hydrocephalus. For this reason it is useful to look at research findings on the language and verbal skills of the wider hydrocephalic population.

Hagberg & Sjorgen (1966), in a study of 84 untreated hydrocephalic cases, reported that one-quarter (25%) demonstrated the 'cocktail party syndrome'. Fleming (1968) matched a group of 11 hydrocephalic children with a control group. The mean chronological age of both experimental and control groups was a little over 6 years. Both groups were asked to describe a set of pictures, and the responses were analysed. The hydrocephalics made more inappropriate responses, but differences were not statistically significant. Fleming concluded that the proportion of inappropriate verbal responses was primarily a function of chronological age rather than mental age.

Parsons (1969), working with a group of hydrocephalic children, compared them to a control group on a test of short-term verbal memory presented as a language repetition test. No significant difference was found.

The pattern of varying research findings in this area is again displayed by the work of Swisher & Pinsker (1971), who had teachers identify 11 hyperverbal hydrocephalic children who were then matched to 11 children who had previously been selected as hyperverbal. The children with hydrocephalus were found to have significantly higher scores than the control group on the Illinois Test of Psycholinguistic Ability (McCarthy & Kirk 1961), which was presented by the researchers as evidence for the existence of the hyperverbal syndrome in hydrocephalic children.

Perceptual and perceptual–motor skills of spina bifida children

In recent years an interest has emerged in the perceptual and perceptual–motor skills of spina bifida and hydrocephalic children. Evidence of the range of effects which may be found as a result of differing visual–motor skills and manipulative skills is accumulating. As this occurs, the study of possible deficit areas indicates the likelihood of a child more developmentally or educationally at risk than was previously known.

Scherzer & Gardner (1971) initially reported that in a small sample of 14 myeloceles, 4 showed discrepancies on the results of the Bender Gestalt Test (Koppitz 1964). A more substantial study was undertaken by Sand, Taylor, Rawlings & Chitnis (1973), who assessed 37 subjects diagnosed spina bifida manifesta aged between 4 and 16 years (15 boys and 22 girls). The distribution of scores on the Frostig Perceptual Quotient (Frostig, Lefever & Whittlesey 1966) was shown to be highly skewed. About two-thirds of the sample fell below the cut-off level suggested by Frostig as demonstrating problems (P.Q. < 90). This tendency was particularly marked in the eye–motor co-ordination and figure–ground subtests.

Hand function in spina bifida children attracted the attention of Grimm (1976), who examined 17 myelomeningoceles aged between 6 and 9 years. A little over 80 per cent of the sample demonstrated significantly lower hand function scores (greater than 2 SD) than scores for age and sex normative groups. Low hand function scores for these children were also demonstrated by Sand, Taylor, Hill, Kosky & Rawlings (1974), Anderson (1976*a*), Anderson & Plewis (1977) and Anderson & Spain (1977).

Perceptual and perceptual–motor skills of hydrocephalic children

There has been a continuing interest in the perceptual and perceptual–motor functioning of hydrocephalic children, apart from those who also experience spina bifida. As early as 1962, Hagberg reported that from his sample of 26 untreated cases of hydrocephalus who apparently had intellectual skills in the normal range, a little under half (12) showed signs of ataxia, including minor tremor and motor disturbances.

Reports of perceptual–motor discrepancy in hydrocephalic subjects as indicated by test results are similar to the results from spina bifida subjects. Miller & Sethi (1971) examined 14 hydrocephalic children of school age (including some with both spina bifida and hydrocephalus) with I.Q.s in the 70–105 range. Bender (Koppitz, 1960 revision) and Frostig Visual Perception Scales were used. No subject obtained an age-equivalent score within 18 months of his chronological age on the Bender test. Highly significant differences were reported between chronological age and age-equivalent scores on both tests. Two problem areas were delineated by the authors: total 'gestalt' difficulty regarding spatial configuration, and difficulty in figure–ground discrimination. These findings appear to parallel to some extent the findings for spina bifida children only (Sand et al. 1973; Scherzer & Gardner 1971), highlighting the possible significance of the perceptual area contributing to impaired perceptual–motor functioning in the hydrocephalic and spina bifida–hydrocephalic populations.

Tew & Laurence (1975*b*) report that shunt-treated hydrocephalic children had appreciably greater difficulty on the items of the Frostig test than children who were not treated with a shunt. More than half failed to score on the test. They point out that poor visuo-perceptual functioning is strongly associated with low intelligence, and in all probability is an expression of it. Only in a few cases did children with I.Q.s less than 70 score on the Frostig scale.

The significance of hydrocephalus to intellectual development is also demonstrated by the work of Gressang (1974), who compared 20 myelomeningoceles with shunts (70+ I.Q.) to 9 myelomeningoceles without shunts (70+ I.Q.) on scores on the Frostig (1966) and Beery (1967) tests, Ayres Space Test (Ayres 1966*a*) and Southern Californian Figure Ground (Ayres 1966*b*) Test. No significant differences between the 2 groups were found except on Frostig Test results, and there, surprisingly, the shunt-treated children scored better than those without shunts. Gressang's results tend to support the contention of Tew & Laurence in regard to the positive relationship between low intellect and low visuo-perceptual skills.

2.3.2 School placement

A limited number of studies, all from the United Kingdom, have looked at existing school placement of spina bifida children or have attempted during the pre-school years of these children to predict school placement requirements. Burns (1967), in a Liverpool survey, reported on 70 spina bifida children with regard to school placement. Regular school placement was maintained by 23 children (33%), 38 children (54%) were placed in schools for physically handicapped children, three (4%) were in other special schools and six (9%) were considered unsuitable for formal schooling.

Tew & Laurence (1972) reported their findings in the school placement of 56 (34 boys and 22 girls) spina bifida children in Wales. Seventy-seven per cent were in regular school placements and 23 per cent in special school placements. When boys and girls were considered separately, it was found that more than 80 per cent of the boys were in regular school placement, while the girls were fairly evenly distributed between regular and special placements.

Spain (1969) based her predictions of school placement requirements on a cohort of children followed from birth. The predictions reported were made on the basis of assessments undertaken when the children were 3 years of age. Some 60 per cent were considered to require special education placements during their school years, and 40 per cent were seen to demonstrate only minor handicap, or have adequate developmental functioning, and be suited to regular school placement. The 60 per cent requiring special education were further classified into *severely* subnormal children with multiple handicaps (10%) and those likely to require places in physically handicapped schools (50%). Some one-third of this latter group were expected to be *educationally* subnormal. A follow-up study at 6 years reported that 40 per cent had been placed in regular schools (Halliwell & Spain 1977).

A more recent North American study (Lauder, Kanthor, Myers & Resnick 1979) produced results more similar to those reported above for Wales, with 60 per cent of the group studied attending regular schools.

2.3.3 School achievement

Little has been reported on the formal school achievements of spina bifida children. Studies in Wales and London appear to be the only evidence available to date.

Reading

Laurence & Tew (1971) administered the Burt Graded Word Reading Test (Burt 1947) to 63 spina bifida children (18 encephaloceles, 37 myeloceles, 17 meningoceles). The meningoceles performed at an average level (mean reading quotient of 94). The myeloceles mean reading quotient was less than average (83), but the distribution of scores displayed greater variance then for the meningoceles. Children with encephalocele had a mean quotient well below average. It would seem that reading achievement scores tend to have the same distribution characteristics as scores on tests of intelligence, when analysed on the basis of diagnosis. While a significant difference in the I.Q.s of boys and girls was found, no similar difference was noted in the mean reading quotients of boys and girls. In general terms, Tew & Laurence (1972) found encephaloceles unable to score on reading tests, and between 35 and 50 per cent of both myeloceles and meningoceles were from 1 to 4 years retarded in reading achievement.

With regard to the effects of hydrocephalus on reading, Tew & Laurence (1975*b*) noted little difference between the reading scores of spina bifida children with hydrocephalus and spina bifida children with arrested hydrocephalus. However, mean scores for both groups were some 6 months behind those of a control group. Shunt-treated hydrocephalic children were significantly poorer readers than children in a control group. Almost two-thirds of the shunt-treated children were non-readers at 7 years of age.

Spelling

Tew & Laurence (1972) appear to have provided the only evidence available on spelling attainment. They claimed that 72 per cent of their myelocele group (n = 32) were from 1 to 4 years retarded in spelling, and 65 per cent of a meningocele group (n = 17) were similarly retarded. In a later study (1975*b*) the same authors found children with a shunt to be significantly poorer spellers than control group children, and poorer than spina bifida children without hydrocephalus on the Schonell Graded Word Spelling Test (Schonell & Schonell 1950).

Mathematics

The 1972 study by Tew & Laurence found 78 per cent of children with myelocele (n = 32) to be more than 1 year retarded in mathematics, while 65 per cent of meningoceles (n = 17) were also more than 1 year retarded.

In regard to the effect of hydrocephalus on mathematics achievement, Tew & Laurence (1975*b*) found spina bifida children with hydrocepahlus to score significantly lower in mathematics than a control group, while shunt-treated hydrocephalic and spina bifida children scored lower than children with spina bifida only. The researchers regarded arithmetic as the school subject in which spina bifida children performed most poorly. They claimed that about one-third of the children with spina bifida were incapable of simple counting at 7 years of age.

Handwriting

Anderson (1976*a*) studied the handwriting of spina bifida children, and reported that handwriting is generally poorer in spina bifida and spina bifida–hydrocephalic children than in non-handicapped children. She suggests that this is due to (a) markedly impaired muscular co-ordination, which is frequently intensified by (b) lack of practice in underlying skills arising from restricted experience in the early years, and (c) the children's difficulties both in processing information received and in organising their movements according to their intentions. An occupational therapy program to treat writing difficulties in these children is outlined by Morrison (1978).

2.3.4 Specific learning problems

Although the survival rate of children born with spina bifida increased dramatically with the development of the Spitz–Holter valve to control hydrocephalus in the late 1950s, reports of research into the learning problems, which many spina bifida children encounter, have not been prolific. Some recent studies have shown that these children have problems in perception (Badell-Ribera, Shulman & Paddock 1966; Miller & Sethi 1971*a*, 1971*b*; Tew & Laurence 1975*b*). Hunt (1973) commented that spina bifida children find writing and drawing tasks especially difficult. Others to draw attention to the problems of poor hand function have been Sella, Foltz & Shurtleff (1966), Sand, Taylor, Rawlings & Chitnis (1973), Parsons (1972) and Anderson & Spain (1977).

An overview of studies examining poor perception or impaired motor skills in spina bifida children reveals that a number of factors may be involved. Among these are low intelligence, the type and effect of hydrocephalus — if it occurs, the level of the lesion, and extent of neurological impairment in the upper limbs. The difficulty in isolating any one cause for perceptual and motor problems lies in the interdependent nature of these factors. Hydrocephalus can result in brain damage and, consequently, impairment of intellect. There is a positive correlation between height of the lesion and presence of hydrocephalus, and between height of the lesion and degree of physical disability leading to restricted movement and limited experience (Sand, Taylor, Hill, Kosky & Rawlings 1974). There is also a positive correlation between height of lesion and degree of upper limb impairment (Wallace 1973).

Tew & Laurence (1975*b*) point out that it has not been established if poor motor co-ordination and deficits in visual perception in children with spina bifida and hydrocephalus are present because of low intelligence. They found a highly significant difference ($p < 0.001$) between the verbal, performance and Full-Scale I.Q.s of their total spina bifida sample and their control group. They judged this as 'confirming evidence that spina bifida generally is accompanied by severe intellectual deficit' (p. 130). This finding conflicted with the study of Badell-Ribera et al. (1966), who concluded that hydrocephalus was the factor mainly responsible for low scores on intelligence tests. Using the WISC or the WAIS they found that the mean verbal, performance and Full-Scale I.Q.s of the non-hydrocephalic group ($n = 28$) were in the normal range. The mean verbal score of the hydrocephalic group ($n = 47$) was also in the normal range, but the difference between the 2 groups on all 3 scores was significant. The mean performance and Full-Scale scores of the hydrocephalic group were below average, the mean performance score being 25 points lower than that of the group without hydrocephalus — a highly significant difference.

A problem evident in the literature that is associated with this research is that of classification. Sand et al. (1974) placed subjects in 1 of 2 categories. The term 'hydrocephalus-present' referred to those whose head circumference equalled or exceeded 2 standard deviations above the mean for the child's chronological age. All others were classified 'hydrocephalus-absent'. Wallace (1973) used presence or absence of a shunt in the criteria for her definition, and she discussed the mobility of children with shunts and head circumference greater than 2 standard deviations above the mean. Comparisons were drawn with the children without shunts whose head circumference was 2 standard deviations or less above the mean. Miller & Sethi

(1971*a*) did not indicate whether subjects in their study were shunted or not, but all had been diagnosed hydrocephalic. Parsons (1972) mentioned that only 12 of the 39 children in his study had shunts, but he did not examine test scores of the shunted group separately. Badell-Ribera et al. (1966) tested 75 spina bifida children, of whom 62 per cent had hydrocephalus, but none had had surgical treatment. The authors suggested that these survivors represent

> the natural history of those children with spina bifida cystica who develop non-progressive hydrocephalus and [they] should serve as a control group for study of those patients in whom surgical treatment of hydrocephalus is provided. (p. 787)

Unfortunately there do not seem to be many studies that compare the three groups, i.e. shunted hydrocephalic children, hydrocephalic children without shunts, and children with spina bifida only. One exception is a study by Tew & Laurence (1975*b*). On the Frostig Test of Visual Perception it was shown that there was an orderly progression of mean perceptual quotations (P.Q.s) for the 3 groups, with the added value of comparison with a control group.

Mean Frostig P.Q.

Hydrocephalic, with shunt	*Hydrocephalic, without shunt*	*Spina bifida only*	*Control*
79	90	96	107

Miller & Sethi (1971*b*) considered the effect of hydrocephalus on brain function. With an increase of intercranial pressure, there is a stretching of the corpus callosum. The results of part of their experiment in tactile matching in which subjects were required to choose with one hand a shape they had felt with the other were poorer than when the same hand was used. This indicates that there is some deficit in communication between the 2 hemispheres of the brain. The authors concluded that 'it is possible that the reduced functional capacity of the corpus callosum may help to explain other functional disorders in hydrocephalus such as poor motor co-ordination'. That this is so is subscribed to by Parsons (1972). He believes that fine voluntary movements of the hands are impaired by damage to the sensory and motor cortex controlling the upper limbs.

There is a positive correlation between the height of the lesion and the degree of hydrocephalus. Sand et al. (1973) found that in their sample of 37 spina bifida children, the higher level of lesion (thoracic$_4$– thoracic$_{12}$) was uniformly associated with hydrocephalus. Those with a lesion in the sacral area were free of hydrocephalus. However, their sample contained only 3 subjects with a lesion between sacral$_1$ and sacral$_4$, which is too small a number to give a valid result. Wallace (1973) divided her subjects into only 2 groups: those with function in the sacral region and those with no function below the lumbar region. Her study would have been more meaningful if frequency tables had been provided. However, it can be determined that some of the 81 children with function in the sacral region had been treated for hydrocephalus.

The higher the lesion, the greater is the degree of paralysis. Consequently there is a relationship between height of lesion and reduction in mobility. With a reduction in mobility comes an experiential deficit (Hunt 1973; Anderson & Spain 1977). There is also likely to be delayed development in manual skill in children with a high lesion, since motor weakness and poor balance cause them to use one hand as a prop when sitting, and little practice is gained for adequate skill development (Hunt 1973; Anderson & Plewis 1977).

Neurological abnormality of the upper limbs has received little recognition in the literature. Badell-Ribera et al. (1966) reported that neurological examination of children in their sample failed to reveal evidence of 'other significant neural malformations' (p. 791), but the authors report that some of the hydrocephalic children had 'hyperactive deep tendon reflexes in the upper extremities, and more rarely, mild inco-ordination in the upper extremities' (p. 791).

Attention was drawn to the presence of upper limb abnormality by Wallace (1973). She found that 69 per cent of her study involving 225 children in Cardiff had neurologically abnormal upper limbs. She lists the types of upper limb disability found as bilateral pyramidal tract dysfunction, cerebellar ataxia, chorea, dyspraxia, mixed pyramidal tract and cerebellar dysfunction, or mixed other disorders. A total of 122 of the 150 children with shunts and 34 of the 75 children without shunts had impaired upper limbs. The purpose of her study was to examine 'the relationship between adequacy of mobility and upper limb function and the presence of hydrocephalus' (p. 84). She does not appear to use a clinical diagnosis but rather the presence of a shunt as the criterion for determining the hydrocephalic subjects. She reported that 122 of the 150 children with shunts and 34 of the 75 children without shunts had impaired upper limbs. Without a more precise diagnosis of the children without shunts, it cannot be concluded from her study that hydrocephalus is the factor that causes neurologically abnormal upper limbs in spina bifida children.

A few studies have examined perception, particularly those aspects tested by the Frostig Test of Visual Perception (Miller & Sethi 1971*b*; Sand et al. 1973; Gressang 1974; Tew & Laurence 1975*b*). It has been shown that children with high lesions and/or hydrocephalus tend to have perceptual problems (Sand et al. 1973; Tew & Laurence 1975*b*; Anderson & Spain 1977). Tew & Laurence (1975*b*) found that two-thirds of their 'spina bifida only' group (n = 20) had normal perceptual abilities, but they pointed out that the pattern of scores on both the Frostig Test of Visual Perception and the WISC were similar and they suspect that the visuo-perceptuo-motor impairment was closely related to low intelligence. Sand et al. (1973) also found that those with age-appropriate perceptual scores were those who had no hydrocephalus, higher I.Q.s and lower spinal cord lesions.

One study that attempted to eliminate the variable of mental retardation has been reported by Gressang (1974). Her sample consisted of 20 spina bifida children with hydrocephalus and 9 children with spina bifida only. She rejected children with an I.Q. below 70 or developmental quotient below 80. Her results were completely contrary to those of other investigators. She used four tests: Frostig Test of Visual Perception, Beery Test of Visual Motor Integration, Ayres Space Test and Southern California Figure Ground Test, and her results showed the hydrocephalic group gaining higher scores than the non-hydrocephalic group. The age range of her sample was 4 years 9 months to 9 years 3 months, while that of Sand et al. (1973) was 4 years to 16 years 7 months. Since the ceiling on the normative scale for this test is 9 years 11 months, Sand et al. used a formula to estimate a scale score for subjects 10 years and over. The problem of small samples was recognised by Gressang and, it seems, by Sand et al., who apparently considered it preferable to use the maximum number of subjects and estimate some scores than to limit the sample to those within the age range for whom normative data was available.

While Gressang's findings were startingly different from others reported in the past few years, she does point out that many children's scores were below the mean for their age level. Ten children scored a scale score of < 50 on the Frostig Test and only 6 children scored at or above age level on the Beery Test of Visual Motor

Integration. Unfortunately this piece of research does not give sufficient information to allow comparison with other studies employing the same instrument — yet the author saw the worth of it as being a challenge to other workers in the field to compare their results with hers. She acknowledged that specific conclusions concerning spina bifida children could not be drawn from it. Unfortunately Gressang believed her work to be a pilot study, she was apparently unaware of the studies by Miller & Sethi (1971*b*) and Sand et al. (1973), which might have led her to examine and present her data in a more meaningful way.

Scores on the subtests of the Frostig Test of Visual Perception revealed that eye–hand co-ordination, spatial relationships and figure–ground perception are likely to be problem areas for children with spina bifida (Sand et al. 1973; Anderson & Spain 1977). Miller & Sethi (1971*a*) found an 18-month lag on the Bender Gestalt Test, and fairly similar results on the Frostig subtests, in their sample of 14 hydrocephalic children. The differences between chronological ages and age-equivalent scores was highly significant.

Two experiments conducted by Miller & Sethi (1971*a*) using their hydrocephalic sample and a control group of non-handicapped children matched for age gave interesting results. They show that the deficit in visuo-spatial perception is not because of motor disability and that the problem in figure–ground perception is 'not an artifact of simulus complexity' (p. 80). It appears to be a more serious degree of a normal difficulty since the controls also had difficulty in rejecting relevant information as the complexity of the task increased.

Miller & Sethi (1971*b*) used another experiment (tactile matching) to examine the deficit in spatial relationships in hydrocephalic children. They compared the mean number of correct responses between the hydrocephalic group and the control group and found a difference significant at the 1 per cent level. The difference for 'crossed' matching (feeling a shape with one hand and selecting a matching shape with the other) was significant at the 5 per cent level. The authors therefore concluded that difficulty in spatial relationships in hydrocephalic children was a general deficit rather than a purely visual one.

Since the spinal cord lesion affected muscles and limbs below the lesion, it had been generally considered that upper limb function would be normal, until Wallace (1973) showed that neurologically abnormal limbs in spina bifida children is not a rare occurrence. No attempts to verify Wallace's findings appear to have been made, and this is surprising in view of medical knowledge that has been gathered concerning the presence of the Arnold Chiari malformation in many children with hydrocephalus. Anderson & Spain (1977) discuss the aetiology of this condition, in which tissue from the lower lobes of the cerebellum is drawn downwards into the opening at the end of the spinal canal. Parts of the brain stem are also elongated and drawn downwards. Movement is controlled by 3 parts of the brain — the motor cortex, the basal ganglia and the cerebellum. Damage to the cerebellum is known to cause poor balance and cerebellar ataxia, characterised by upper limb muscle weakness, disturbance of voluntary movement and errors in the direction, force and rate of movement.

Reports of research into hand function in spina bifida children are few, the most important to date having been associated with the work of Anderson and Sand. The research established a relationship between poor hand function and the presence of hydrocephalus (Sand et al. 1974; Anderson 1976*a*; Anderson & Plewis 1977; Anderson & Spain 1977), and while the factors causing poor hand function in spina bifida children have not been identified, there was confidence that specific training programs will help overcome these problems (Sand et al. 1974; Anderson & Plewis 1977). Practice was shown to result in an increase in scores in the experiments conducted by Anderson & Plewis (1977), although the extent of improvement was related to intelligence. A developmental intervention program to prevent deficits in upper limb function has been put forward by Rosenbaum, Barnitt & Brand (1975). The above needs to be compared with Wallace's (1973) finding that 45 per cent of spina bifida children without hydrocephalus had upper limb abnormality.

Observation of poor co-ordination and immature hand function led to the investigation of the extent of these disabilities using the Developmental Hand Function Test. This is an objective test for adults devised by Jebsen, Taylor, Trieschmann, Trotter & Howard (1969), and has been found to be reliable and clinically useful. It was later standardised for use with North American children over the age of 5 years by Taylor, Sand & Jebsen (1973). The test contains 7 subtests: (1) writing a short sentence; (2) turning over 76 x 127 mm cards; (3) picking up small objects and placing them in a container; (4) stacking checkers; (5) simulated eating; (6) moving empty cans; (7) moving weighted cans. Each task is performed using first the non-dominant hand and then the dominant hand. The score obtained is dependent on the time taken to complete each task.

Sand et al. (1974) tested 25 children on 6 of the subtests (the writing task was not given). The age range of the group was 6–19 years, and they were divided into 2 diagnostic groups: hydrocephalus present (n = 16) and hydrocephalus absent (n = 9). The criterion for allocation to groups was head circumference: those with a head circumference more than 2 standard deviations above the mean were classified as hydrocephalus-present. The results were also examined in relation to intelligence and again 2 groups were formed: those with I.Q. 80 and above and those with I.Q. 79 and below. Only 5 children fell into the latter category and it is not shown into which diagnostic group they fall.

Anderson's findings (Anderson 1976*a*) from a detailed study of cognitive and motor deficits in children with spina bifida and hydrocephalus, with special reference to writing difficulties, are also relevant here. Her samples consisted of 29 children with spina bifida and shunt-controlled hydrocephalus, and 29 non-handicapped children, matched for intelligence, age and sex. She found that the scores of the controls on the Developmental Hand Function Test were close to the North American norms, while the spina bifida children performed poorly, two-thirds of them being markedly slow. Two subtests reported to have presented the most difficulty were Subtests 3 and 5. Subtest 3, picking up small objects and putting them in a container, involved fine finger movements and good hand–eye co-ordination. On Subtest 5, simulated eating, children held the spoon awkwardly and could not orient it correctly. Sand et al. (1974) found that this task presented most difficulty to the hydrocephalic children in their study. Their mean time was 16.2 seconds longer than the norm for the dominant hand and 21.5 seconds longer for the non-dominant hand.

A delay in the development of hand preference in spina bifida children has been reported (Spain 1974; Anderson 1976*a*; Lonton 1976). Anderson & Spain (1977) have produced a table showing an 'abnormally low proportion of pure right-handers in the spina bifida group and an abnormally high proportion of mixed-handers and left-handers' (p. 137). The reasons for this are not clear but it may be that with damage to the corpus callosum and consequent interference between the 2 hemisphers of the brain, failure to establish laterality will occur. It may also be a sign of neurological immaturity or a lack of opportunity for adequate skill development in the early years. The authors point out, too, that failure to develop hand preference is likely to retard manual skill development.

Anderson has been the only research worker in the field to have undertaken a study of both motor skill and handwriting skill in spina bifida children. Using a replication of a study designed by Connolly et al. (1968), Anderson & Plewis (1977) found that children with spina bifida and hydrocephalus showed marked impairment of speed on a target (dotting) task. They observed that some children grasped the pencil in an immature way or held it too tightly, and that some had difficulty controlling the forcefulness of movement. It was also observed that a slow reaction to the word 'Go' caused a reduction in speed on this dotting task.

Anderson (1976*b*) lists the components of graphic ability as (a) receptor efficiency, (b) sensory organisation, (c) effector efficiency, (d) motor organisation. She suggests that deficiencies in each of these components are likely to occur in spina bifida children. The least likely to seriously affect their handwriting skill is receptor efficiency, although it is known that hydrocephalic children are prone to visual defects. Tests of visual perception have shown that these children do have difficulty in organising and interpreting sensory input, yet writing tasks require unimpaired sensory integration skill. Poor effector efficiency (lack of muscular control) has been shown to result from damage by hydrocephalus to the cerebellum and the motor cortex. Restricted movement and lack of opportunity to practise skills is also a possible cause. Poor motor organisation, indicated by the child's inability to organise movement in space, results in poor spatial quality in writing. Poor performance in a test of spatial relationships and delayed development of hand preference are signs of this aspect of graphic disability.

In an analysis of tracing and handwriting tasks, speed, spatial qualities and letter formation qualities were examined by Anderson (1976*a*). Twenty children with spina bifida and hydrocephalus, aged 8–10 years, were individually matched with a non-handicapped child. The spina bifida children were markedly slower than their controls, and in two-thirds of the pairs, the non-handicapped child was judged to be the better writer. When an objective scoring method was applied to assess alignment of words, spacing of words and letters, formation of letters, uniform size and slant of letters, and quality of stroke, there was a significant difference between the 2 groups. Sixteen of the spina bifida children and 8 of the controls scored below 80 (Anderson & Spain 1977).

Small numbers in the samples in almost all the research that has so far been undertaken into the learning problems facing spina bifida children is a limitation of the studies. In addition there are many compounding variables to control. Another major problem is that so few studies have been undertaken. Because of the interrelatedness of learning and motor problems for these children, a multidisciplinary approach to researching the area is needed in the same way that multidisciplinary treatment is needed to ensure for them maximum quality of life.

2.4 FAMILY–SOCIAL ASPECTS OF SPINA BIFIDA AND HYDROCEPHALUS

2.4.1 Introduction

Comparatively little research has been undertaken into the social and emotional effects of spina bifida. Those studies that have been conducted look at the problems from 2 distinct viewpoints:

(a) the effect on the family where a spina bifida child is a member; and
(b) the effect of the disability on the social and emotional development of a person born with spina bifida.

Of these 2 broad areas, considerably more attention has been paid to date to the effect of a spina bifida child on the family, particularly on the stress borne by the mother and the strain on marital relationships (Hare, Laurence, Payne & Rawnsley 1966; Richards & McIntosh 1973; Martin 1975; Spain 1973). More recently some attention has been paid to the effect on siblings (Parfit 1975; Anderson & Spain 1977). Only a few studies, notably by Dorner (1976), Laurence & Beresford (1975), Evans, Hickman & Carter (1974) and Scott, Roberts & Tew (1975) have examined the social and emotional problems of the adolescent and adult with spina bifida.

2.4.2 Social class and socio-economic status

It has been reported that spina bifida tends to occur more frequently in families of low socio-economic status; those who are least well equipped materially to cope with the added burden of a handicapped child. The British studies generally use a 5-point rating of socio-economic status based on parents' occupations, Classes I and II being the higher occupational levels, Class III being designated for non-manual and manual workers, and Classes IV and V being unskilled workers and pensioners. This broad categorisation is used in the following section of the review.

A study undertaken in the Newcastle-on-Tyne area by Walker, Thomas & Russell (1971) employed a sample of 107 children aged 2 years and under. Only 1.9 per cent of the parents were in occupations in Classes I and II (criteria for allocation being the occupation of the father) and 31.8 per cent were in Classes IV and V, leaving two-thirds of the children with fathers whose occupations were in Class III. Spain (1973), with a sample of 150 London children aged 2 years, found a higher proportion (14%) of families in Classes I and II, and 33 per cent in Classes IV and V. Spain compares her figures with the Greater London area census figures for 1961, which reported 20 per cent of the population in Classes I and II, and 26 per cent in Classes IV and V. In Woodburn's (1973) South-East Scotland study, 86 children aged between 18 months and 16+ years were included. In her sample, the distribution by social class approximates Spain's findings, the figures being respectively 12.8 per cent and 34.8 per cent of families in Classes I and II, and IV and V, while Williamson (1965), in a Southampton study, reported 67 per cent of families in occupational Classes I and II, and 30.5 per cent in Classes IV and V.

These findings indicate that many families of spina bifida children are trying to cope with insufficient financial resources, and with the worry that is generally consequent to such a situation. It appears to be of great importance that adequate financial support be available to affected families, taking into consideration the added expense reportedly incurred in caring for a child with spina bifida. Families with a handicapped child tend not only to be financially less well off, but also to be unsure of how to obtain services to which they are entitled.

However, the picture portrayed by the above United Kingdom studies may be different in Australia. In a Melbourne study by McAndrew (1974), undertaken during 1972–74, it was reported that 19.1 per cent were in social Classes I and II (compared with 2 per cent reported by Walker et al. 1971), and 21.4 per cent were in Classes IV and V, compared with 32 per cent in the Newcastle-on-Tyne study. A more recent and detailed study of social class and other secular trends evident from a study of 1575 cases of neural tube defect has been undertaken in New South Wales (Field 1978), with results generally parallel to those from Northern Hemisphere studies.

2.4.3 Housing

The criteria for suitable housing for families with a handicapped child — ease of access, a single-level (near ground level) dwelling, accessibility of bath and toilet, good hot water supply and adequate space — does not present the same problem in this country as it does in the more closely populated areas of urban Britain, except perhaps in the availability of single-level (near ground level) dwellings. The problem of obtaining suitable housing in Britain appears to be a major one.

Walker et al. (1971) and Spain (1973) found 29 per cent of their study populations in poor accommodation, while approximately 30 per cent owned their own home. Spain reported 16 per cent in rooms or flats which were not self-contained. She compares her sample with the general population in the Greater London area, where only 4 per cent of families are in similar poor housing and 46 per cent owned their homes. About 50 per cent of Spain's sample had moved their residential location at least once following the birth of a spina bifida baby. Richards & McIntosh (1973) studied the families of 86 children between the ages of 2 and 6 years in Glasgow. Of this sample, 41.9 per cent had moved their home at least once. Freeston (1971) and Hunt (1973) reported that 33 per cent of their sample of families had moved their place of living.

Woodburn (1973) also studied the problems of suitable housing and reported that 'the quality of the house in which the family with a spina bifida member lived, was found materially to affect their daily living' (p.143). In her study, only 17.6 per cent owned their homes, 28.4 per cent found housing arrangements entirely suitable, while 47 per cent of housing was unsuitable because of the child's handicap. Of this group, 56.5 per cent reported disadvantages in the design of their housing, the most serious being because of the need to negotiate steps either externally or internally. Other problems reported were doors too narrow for wheelchairs, dampness and cold and difficulty of access.

Another area of housing considered by Woodburn was the sufficiency of amenities. Fifty-four per cent of families reported problems in this area, the most serious being inaccessibility of the toilet (18.9%), while 5.4 per cent had no bath and 9.5 per cent had no accessible garden or play area. In reporting on the size of their homes, 77 per cent of the group had no cause for complaint, 16.2 per cent were in overcrowded conditions, and another 6.8 per cent were hampered by lack of space for the spina bifida child. In looking at the suitability of the location of residence, Woodburn found 54 per cent of families were satisfied with their situation. The main reasons for dissatisfaction of the other 46 per cent, in respect to location, were isolation from hospital (17.6%), isolation from school (8.2%), and hilly areas impeding mobility (9.5%).

Richards & McIntosh (1973) studied 86 Glasgow families whose spina bifida children were born between 1964 and 1968 and of whom 72 per cent lived in tenement flats, 10.5 per cent lived in high-rise flats, and 18.6 per cent lived in homes of only 1 or 2 rooms. However, the authors comment that this last figure is well below the average population figure of about 40 per cent for all Glasgow families. While these results suggest that many families with a handicapped child in Glasgow have unsuitable housing, the authors of the study did not report the degree of parental satisfaction or dissatisfaction with the type of housing in which they are accommodated.

2.4.4 Financial stress

The extent to which a handicapping condition causes financial hardship is a question to which there is no simple answer, since it is relative to the individual family's aspirations and ideas of what constitutes basic necessities, and the point at which the division between financial hardship and minimal financial security should lie. It can be safely said, however, that considerable extra expense is incurred in providing for the needs of a spina bifida child.

The costs of clothing and transport were the main areas of additional family expense reported by Freeston (1971), Richards & McIntosh (1973) and Woodburn (1973). Frequent replacement of clothing due to hard wear, extra clothing because of incontinence, and sometimes special types of clothing were mentioned by 55 per cent of mothers as reasons for extra expense in Woodburn's survey.

Freeston, whose study was conducted in Sheffield with a sample of 85 families, reported additional expense incurred by 33 per cent of families in moving house because of the spina bifida child, and a number had acquired a car because of the difficulty of using public transport. Of Woodburn's sample, 66.2 per cent of families saw transport costs as being a major area of additional expense, the main item being the cost of fares to visit the child when in hospital or to take him or her for out-patient treatment (57%).

Woodburn also discusses the need for frequent parent visiting when a child is hospitalised — for therapeutic rather than social reasons — and she believes that reimbursement of costs should be a government responsibility, whether it be a refund of public transport fares or a mileage allowance for a private vehicle. She pointed out that ownership of a car did not necessarily mean affluence, as many people regarded the purchase of a car as the only way in which the family could manage transport for their handicapped child and provide outings for all the family.

2.4.5 Family size, birth order, residence and age of parents

Spain (1973) found that families with a spina bifida child were no larger than average, but that there were greater proportions of younger mothers (< 20 years of age) and older mothers (40+ years) of these children than in the general population. Figures given in the 1961 census in the Greater London area showed that 4 per cent of all births were to mothers under the age of 20 and 1 per cent to mothers over forty. Spain (1973) and Woodburn (1973) both found that 10 per cent of mothers of spina bifida children were under 20 years of age, while Walker et al. (1971) found 14.9 per cent of mothers in this category. In Spain's sample, 4 per cent of mothers were over 40, Walker et al. reported 15.9 per cent over the age of 34, and Woodburn, 5.8 per cent over the age of thirty-five.

In the studies in London (Spain 1969) and South-East Scotland (Woodburn 1973), 40 per cent of spina bifida babies were 1st-born, while in the Newcastle study (Walker, Thomas & Russell 1971), it was reported that the majority of spina bifida births were either 1st- or 2nd-born. Williamson (1965) found 50 per cent of her sample of 59 cases were 1st-born and a further 18.6 per cent were 2nd-born. Field (1972) reports that 43.2 per cent of spina bifida children were 1st-born.

These figures point to the need for a great deal of support for the young mother faced not only with handling and caring for a baby for the first time but handling and caring for one with the added complication of serious disability (Spain 1973).

Walker et al. (1971) quote the mean ages of their sample of parents at the time of the child's birth as 29.5 years for fathers and 27.1 years for mothers, while Williamson's (1965) figure for mean maternal age is 28.5 years. Woodburn noted that more than half of the mothers in her sample were aged between 20 and 27 years at the time of the child's birth.

It appears that the number of children in residential care is relatively small. Richards & McIntosh (1973) report 2.3 per cent of their sample in residential care; Freeston (1971) reported 4.7 per cent; while in Spain's (1973) study, 4.3 per cent of children were in residential care at the age of 2 years, compared with 2.4 per cent living in a 1-parent family, 91.5 per cent in a 2-parent family, and 1.8 per cent with foster parents.

2.4.6 Parents' reaction to birth of child

The first reaction of parents to the news of the birth of a malformed child is generally reported to be one of shock, grief and confusion (Walker et al. 1971; Hare et al. 1966;

Woodburn 1973; Anderson & Spain 1977). Less than half of the parents in Freeston's (1971) study had heard of spina bifida before the birth of their child, but few knew how the condition would affect the child.

The complex problem of who should tell the parents that the mother has given birth to a handicapped child, when the information should be given and how much should be told is one for which no general solution exists. It would appear that an estimation of the ability of each individual parent to cope with and absorb the information should govern the amount told. Sympathy, understanding and support, not only at the time of advising the parents but also in the days following the birth, are universally needed. The majority of mothers do not understand the implications of the condition when they are first told (Richards & McIntosh 1973; Hare et al. 1966; Freeston 1971).

Opinions vary as to whether the mother should be told immediately after birth of the child. Although the majority of mothers typically are pleased to have early information, many fathers believe their wives should be told later (Hare et al. 1966). About half the mothers in the Glasgow study (Richards & McIntosh 1973) were dissatisfied with the amount of information they had been told. Many parents interviewed by these researchers had not been told of the disability, while in D'Arcy's (1968) report, mothers are said to have complained that they had merely been told that their baby had spina bifida as if they would understand what that meant. In Hunt's (1973) Cambridgeshire study mothers spoke of having many unanswered questions and misunderstood replies, and a general lack of information. Parents generally resented the minimising of the seriousness of the condition (e.g. explanation of spina bifida as 'an extra layer of skin'), particularly when the level of activity and sense of urgency that often developed in the labour ward made them fearful of not having been told the truth.

Woodburn (1973) made a very comprehensive study of this problem, but the diversity of the replies to questions relating to the timing of information, the source of information, and recommendations for the meeting of parents' needs at this time only serve to emphasise the complexity of the problem, mainly because it is a deeply personal one for each individual parent. Woodburn, summarising the needs of the mothers, states that they have need for:

(a) a controlled professional attitude on the part of the staff; and
(b) consideration and understanding of their emotional needs.

Honesty, sympathy, understanding and patience in helping parents come to grips with the reality of a handicapped child in the first few days after birth are basic needs. Mothers appreciated the efforts made by medical practitioners to explain in simple language what was involved. Most mothers need to have information repeated, for it is likely that few can assimilate all that is told to them on that first occasion.

No general suggestion has been derived to best meet the emotional needs of mothers, since each reacts differently. Some others in Woodburn's study felt the need for privacy; others wanted company. Both Woodburn (1973) and D'Arcy (1968) comment that mothers remembered, with a great deal of gratitude, small acts of kindness to them during the first days after the birth of their babies.

According to some writers, grief and the need to mourn are the underlying factors in whatever reaction is evident in parental behaviour (Kennedy 1970; Bentovim 1972; Mackeith 1973). That parents need support to work through their grief is generally acknowledged. However, opinions vary as to the value of mother–child separation. Most authors regard early separation of mother and infant as detrimental to the formation of a normal mother–child relationship. Kennedy (1970) held the opposite view after examining closely the behaviours of mothers who have given birth to a defective baby. He defined the stages of the grief process as protest (shock, disbelief, bewilderment), despair (disappointment, loss, sorrow, guilt) and withdrawal (fantasising the expected normal baby and catharsis of the defective baby). He found that having immediate care of the defective baby interrupted the grief process, and concluded that mothers may need a period of separation from the baby in order to work through feelings of loss.

2.4.7 Parental stress

Of the sample of families studied by Richards & McIntosh (1973), 11.6 per cent attributed illness in the parents to having had a handicapped child. Some 8.1 per cent of mothers and 4.6 per cent of fathers had developed neurotic symptoms. This is a considerably small number when compared with reports from other studies. McAndrew (1974) records that 56.9 per cent of mothers studied had poor health which they attributed to the burden of caring for a handicapped child. In this Melbourne study, 27.4 per cent of mothers had received psychiatric treatment since the birth of the child. Walker et al. (1971) also report a considerable degree of worry and depression affecting the health of parents in these circumstances, particularly of mothers, although in Woodburn's (1973) report it is stated that the general health of the majority of mothers was good. Nevertheless, about half of them mentioned minor worries, most often 'nerves or depression' which were not serious enough for them to seek specialist treatment.

Hare, Payne, Laurence & Rawnsley (1972) found a positive relationship between degree of handicap and extent of maternal stress. Using Maudsley Personality Inventory Scores, which measure extraversion and neuroticism, they found that the neuroticism scores of mothers increased markedly over a period of 2 years when their child's handicap was rated moderate or severe, but there were no appreciable differences in parents of children with mild disability, and no difference whatsoever in the parents of a control group of normal subjects.

Tew & Laurence (1975*a*) used the Malaise Inventory (Rutter, Tizard & Whitmore 1970) to determine the relationships of stress in parents of handicapped children to measures of severity of handicap, incontinence, schooling and intelligence. They found no significant differences in the scores of parents of mildly handicapped children (who could walk unaided and were totally continent) and those of moderately handicapped children (who walked with the use of aids and who were partially continent, or whose incontinence was controlled by a surgical procedure). There were, however, significant differences when comparisons were made with the scores of parents of severely handicapped children (who were either chair- or bed-bound, totally incontinent and frequently with sensory defects).

In this study, incontinence was found to be a factor in high levels of maternal stress, regardless of whether the child had undergone surgery for a urinary diversion. It was reported that 'surgical interference of the genito-urinary system appears to have an emotional effect on the mothers of girls so treated' (p. 29). There were also significant differences in stress scores of mothers whose children attended regular schools and those with children at special schools. Having to send a child to a special school causes many mothers a good deal of anxiety. Similarly, mothers of children whose intellectual functioning was assessed at below average showed greater signs of stress than did mothers of children of average or better than average mental ability.

Burden (1980), also using the Malaise Inventory, reported that the birth of a handicapped child places high levels of stress on most families, and that the likelihood of mental ill health in the child's mother increases enormously. Burden, however, warns about accepting this as a simple relationship, and suggests that the birth of such a child is a 'critical experience' which reacts with others and the mother's personality in determining future health.

Dorner (1975) found that 31.6 per cent of mothers of adolescent spina bifida children suffered more depression than was usual in mothers of similar age without a handicapped child, but maternal depression was not related to the handicapped child's degree of mobility. He concluded that these mothers are more vulnerable to stress, and are consequently less able to cope with other problems that arise from continued long-term care of a handicapped person.

Kolin, Scherzer, New & Garfield (1971) found that the severity of the handicap was not a crucial factor in parental adaptation. They found that only those parents who had at least 5 years' experience of a stable marriage relationship could cope adequately with the presence of a handicapped child, and those parents who had planned the pregnancy were among the group with the highest level of adaptation. Mothers who showed fair-to-poor levels of adaptation were anxious and suffered feelings of guilt and depression.

2.4.8 Parental attitudes to the child

Reports of rejection of the handicapped child are fairly rare, although occasional studies indicate that parents could not come to terms with their child's deformity (Freeston 1971; Martin 1975). Children who are placed in residential care or in foster homes were most frequently children from 1-parent families (Richards & McIntosh 1973; Spain 1973; Hunt 1973; Hayden, Shurtleff & Broy 1974; Martin 1975) or children who have an associated intellectual handicap (Spain 1973). The reported percentage of children living away from their natural families in Britain was small, ranging from 2.3 per cent to 7.7 per cent over a number of studies. In Spain's (1973) sample, most of the children in residential care had contact with their parents, only 2 children (1.3%) having been abandoned.

In an American study by Hayden et al. (1974), however, 17 per cent of the children were not living with their natural families, 2.8 per cent were in institutions for the retarded, and 14.4 per cent were in foster homes. In contrast, only 0.4 per cent of all children born in the United States in 1968 were placed outside their natural families. Yet the above results are comparable to the 14.7 per cent of handicapped children who had been placed outside their natural families reported by Martin (1975) from a study in Missouri. These figures may, of course, reflect the high rate of marriage breakdown reported in the American studies compared with those in Britain.

Hayden et al. (1974) found that parents in lower socio-economic circumstances were more likely to look for alternative placement for their child, and that these parents were less likely to be able to face coping with a physically handicapped child if there was an additional intellectual handicap. They put forward the view that placement of a child outside the family should be seen as a 'positive therapeutic alternative for the child and his family' (p. 253), and a socially acceptable decision — a reversal of the notion that words such as rejection and abandonment imply in many studies which explore this aspect.

2.4.9 Parental expectations

Almost every mother in the Richards & McIntosh (1973) study wanted her baby to live after the initial shock reaction, while some mothers admit to having at some stage wished it otherwise. Mothers in the Hare et al. (1966) study are reported to have been anxious when the baby was in hospital, and much happier when they could look after it themselves. Hare and colleagues reported that mothers do not see their babies as grotesque-looking, even when others do.

An alarming number of mothers (79%) in the Richards and McIntosh study stated that they expected either a cure or a reduction of handicap in the future; 68.6 per cent reported they worried about the child's future. Education presented as the greatest concern to parents. The majority wanted regular schooling and were afraid that special school placement would mean that their child would be educated with mentally handicapped children. Many felt that a stigma was attached to special schools, and that they would be embarrassed to have a special school bus call for their child.

2.4.10 Stress caused by medical needs

Since the parents of spina bifida children are faced with an almost inevitable need by their child for constant medical attention and frequent hospital admission, there are many stressful situations that confront parents, particularly in instances where families rely on public transport and where there are other small children in the family to be considered (Freeston 1971; Anderson & Spain 1977). Mothers appear to appreciate a social worker's advising them what to expect prior to their initial attendance at a combined therapy clinic where children with all types and degrees of disability attend. Parents also appreciate home visits, since they find that they are better able to discuss their problems in the relaxed atmosphere of their own homes (Freeston 1971). Walker et al. (1971) also comment on the fact that while many parents are aware of the need for combined clinics, and are grateful for them, they nevertheless find attendance a trying emotional experience.

In the British studies, the majority of children are reported to attend hospital out-patient clinics, despite the provision of other health services such as community health centres and health visitors. The visiting services appear to be inadequate (Richards & McIntosh 1973; Spain 1973). However, it does seem that attendance at one centre prevents confusion and the problems that arise from conflicting advice or information. Very few parents relied on their general practitioner for medical treatment except for routine medical matters not related to the handicap (Walker et al. 1971; Richards & McIntosh 1973; Spain 1973).

Most parents considered that, medically, the best was being given their child (Walker et al. 1971; Richards & McIntosh 1973; Spain 1973; Anderson & Spain 1977). Richards & McIntosh (1973) reported that lack of physiotherapy was a contentious area. Many parents blamed their child's poor mobility on what they saw as inadequacy in this area of service provision.

Communication between professional persons and families is a major and complex problem, and many parents are impeded in it by their response to the overawing atmosphere of combined clinics and hospital out-patients departments. Consequently, they fail to obtain the information they most want (Hare et al. 1966; Walker et al. 1971; Spain 1973; Woodburn 1973; Anderson & Spain 1977). A plea has been made for the use of simple language so that parents can gain a better understanding of their child's disability and can face a consultation with less emotional tension (Walker et al. 1971; Woodburn 1973). Woodburn deals at length with the complexities of this problem, and reports that 61 parents in a South-East Scotland study listed 100 areas in which they needed more information and guidance. Of these, prognosis was a major concern, with parents being unsure of what the future might or might not hold for their child. Problems of communication have led some parents to expect a 'cure' (Richards & McIntosh 1973) or to believe that a urinary diversion was only a temporary measure (Kolin et al. 1971; Woodburn 1973). Not only are an understanding and acceptance by the parents of a spina bifida child's condition necessary, but an understanding of the implications of the condition is equally important (Woodburn 1973).

2.4.11 Effect on siblings

Few studies have looked closely at the effect of a handicapped child on his or her siblings. Woodburn (1973) comments that it is difficult to gauge this effect, which of course would vary according to the ages of the siblings and also depend on many other factors, particularly parental attitudes.

In the study by Richards & McIntosh (1973), 8.1 per cent of siblings were reported to have responded in resentful, jealous or cruel ways, but some 73 per cent were reported to be understanding and helpful to the handicapped child. Walker et al. (1971) found that 18.7 per cent of their study group showed marked adverse affects from having a spina bifida sibling, while another 5.6 per cent became excessively involved with the handicapped child. With some older siblings, the results are seen in anxiety and worry about the problems faced by their parents; however, in some cases parents have to rely on older children to help at home to a greater degree than would normally be expected (Walker et al. 1971; Hunt 1973). Woodburn reported some positive effects from these family situations — 14 per cent of parents believing that having a handicapped sibling made their non-handicapped children more sensitive and understanding of others. In McAndrew's (1974) study, 31 per cent of parents held this view. Walker et al. and Woodburn report that many siblings show signs of anxiety and stress when the handicapped child is hospitalised.

In discussing the needs of siblings of handicapped children, Parfit (1975) held that older siblings require information, emotional help and education about the condition and its effects on the handicapped child and family. In contrast, the needs of younger siblings are seen to differ as they 'grow up' within the family group and gradually become aware of their handicapped brother or sister through the reactions of friends, and through developmentally overtaking the handicapped child. Parfit suggests that information should be given to siblings freely as well as accurately. They need to be helped to know how to explain their family situation to teachers, friends and other adults, so that understanding and acceptance by others are the outcome.

As siblings grow up, they should receive genetic counselling in order to understand the implications for their own futures and should be involved in discussing the future plans for their handicapped sibling. The need for emotional support for siblings is seen by Parfit as basic in all families of spina bifida children, as feelings of jealousy, resentment, hostility and guilt can readily develop or, on the other hand, over-control of emotions to avoid worrying parents can be equally damaging to their emotional adjustment. An awareness by parents of possible problems and suitable action which can be taken by them is suggested by Parfit, in order that the emotional needs of siblings can be adequately met. Parfit sees the need for education as equally important and suggests that siblings be involved to some extent in the training programs devised for the handicapped child.

2.4.12 Reaction of relatives and neighbours

Reports of the reaction of relatives and neighbours vary considerably, although it is generally noted that grandparents, and particularly the maternal grandparents, play a major supporting role (Woodburn 1973; Walker et al. 1971). Field (1972) comments on the fact that the extended family, with active participation of the grandparents, provides a large measure of support during times of crisis. McAndrew (1974) found that of families who were in touch with maternal grandparents, one-third reported no change in family relationships, one-third believed that there had been signs of non-acceptance of the handicapped child, and the remaining third found grandparents helpful and supportive. This latter group considered that the spina bifida child was responsible for a close bond that had developed between parents and grandparents. However, paternal grandparents tend to show far less acceptance; McAndrew quotes 75 per cent of those in contact with paternal grandparents as having found some degree of non-acceptance.

Walker et al. (1971) record that only 26 per cent of families in their study received help from neighbours; others felt that curiosity rather than concern was a general attitude among those who lived nearby. This is in contrast to the results reported by Richards & McIntosh (1973) and by Woodburn (1973), who reported that 60 per cent of families found relatives, neighbours and friends understanding and helpful.

Woodburn (1973) and McAndrew (1974) also report in detail on the reaction of parents to distressing comments stemming especially from strangers. A high proportion (approximately 79%) of families could also relate instances of unkindness. Woodburn found that less sympathy was extended to a child with poor mobility if he or she was not wearing walking-aids. Calipers tended to induce a sympathetic reaction. The need for increased public education in the acceptance of handicapped persons was emphasised by both Woodburn and McAndrew.

2.4.13 Effect on family–social relationships

Social contacts

It is almost inevitable that the presence of a physically handicapped child places restrictions on the parents' social life, particularly when the child is young. However, 63.1 per cent of parents in McAndrew's (1974) study and 57.5 per cent of parents in Dorner's (1975) study felt that their social life had not been restricted in any way. Fourteen per cent of parents in Woodburn's (1973) research reported that their spina bifida child had increased their social contacts, while 31 per cent believed that their child imposed limitations on their opportunities for social contacts. Anderson & Spain (1977) indicate that in their London study only 40 per cent of parents of 3-year-old spina bifida children went out socially once a month, and less than 20 per cent once a week. The main difficulty with social outings appeared to be the parents' reluctance to leave the child with anyone other than a close relative.

Family relationships

The birth of a spina bifida child can be expected to impose severe strain on both parents. Signs of stress may be evident in total family relationships — between husband and wife, between parents and their handicapped child, between parents and their other children and between the spina bifida and his or her siblings.

The most far-reaching of these potential difficulties is the effect of stress on marital relationships, since this in turn affects the entire family.

Marital relationships

Many parents have reported that the presence of a spina bifida child in their family brought them closer together (Hare et al. 1966; Walker et al. 1971; Martin 1975; Anderson & Spain 1977). Woodburn (1973) records that 31 per cent of mothers interviewed believed that the presence of a handicapped child strengthened their marriage, while 13.7 per cent estimated that it had weakened it.

A number of British studies have reported that the extent of marital disharmony in families with a spina bifida child is not significantly greater than in the general population (Freeston 1971; Hare et al. 1966; Walker et al. 1971). However, in these studies, the length of time that parents had been coping with a disabled child was relatively short at the time of interview. In Freeston's sample of families the affected children were 4 years of age and under, Hare et al. interviewed 120 parents at

6-monthly intervals for only 2 years, and Walker et al.'s sample of 107 children were under the age of 3 years. Further, these studies drew their conclusions mainly from the reported number of marriage breakdowns; in Freeston's study 3 marriages out of the 85 families interviewed had failed, 2 of which were attributed at least partially to other factors. In the study by Hare et al., only 3 of the 120 families involved had a complete breakdown of marriage reportedly as a result of having a disabled child. In Walker et al.'s sample, 2 of the 3 marriages that had broken down completely were at risk before the birth of the spina bifida children.

Dorner (1975) studied a group of 63 families with a spina bifida adolescent aged between 13 and 19 years, and his findings agreed with those already discussed. In 5 cases of marriage breakdown in his research group, the mothers did not feel that the presence of a spina bifida child caused the breakdown. Similarly, in Woodburn's (1973) study, parents whose marriages had ended believed that their marital problems were not due to their handicapped child.

On the other hand, a very comprehensive study by Tew, Payne & Laurence (1974) produced results which indicated that the 'birth of a child with spina bifida seems to present a serious challenge to the stability of a matrimonial relationship' (p. 97). In that study, marital harmony was assessed on a 5-point scale after the birth of the handicapped child and again 9 years later. The subjects were an index group of 59 families, each with a child with a neural tube defect, and 58 control families in which the child involved did not have a neural tube defect. The pairs of children were matched for domicile, social class, sex of the child, and family size. They found that by the time the child was 9 years old, 79 per cent of parents in the control group had satisfactory relationships, but only 46 per cent of parents in the experimental group had satisfactory relationships. The divorce rate in the experimental group was high, at a rate of 13.2 divorces per 1000 marriages per annum, compared with 5.7 per 1000 in the control group and with the national average at 7.1 per 1000 per annum. Remarriage was less frequent in the experimental group, with only 1 of the 7 divorced mothers remarrying, while all 3 of the divorced mothers in the control group had remarried. It was also reported that a mother who is pregnant at marriage and who gives birth to a handicapped child is more likely to have a breakdown of marriage than if the child had not been handicapped (see also Tew, Laurence, Payne & Rawnsley, 1977).

Tew, Payne & Laurence (1974) also discussed the problem of risk for parents whose devotion to their handicapped child leads them to ignore their own needs. Of their sample, 29 families whose marriages were stable at the time were described as 'too cohesive'; that is, parents who 'exaggerate their parental role at the expense of their personal role' and for whom 'all activities are subordinated to the needs of the handicapped child' (p. 96). The authors see this as producing undesirable behaviour (egocentricity and excessive dependence) in the child and as a danger to the mental stability of parents and siblings. They see these marriages as seriously 'at risk' and likely to disintegrate if the child is removed.

Two American studies which present opposing findings are by Kolin et al. (1971) and Martin (1975). Kolin reported a high incidence of marriage breakdown, which involved 6 of the 13 cases (46%) studied. He compared this with a rate of 25 per cent in a New York hospital out-patient sample matched for age, sex, religion and social class. Martin compared a group of 34 spina bifida children under the age of 14 with a group of 60 diabetic children and 59 children who attended the same medical centre for treatment for minor ailments only. Although 26.6 per cent of parents of the children with spina bifida were divorced, compared with 17.4 per cent of the non-handicapped group and 11.7 per cent of parents with diabetic children, Martin states that the divorce rate of families with a spina bifida child is not significantly greater than in the general population. Similarly, in Australia, Field (1972) reports that the divorce rate of parents with a spina bifida child is not high. She found that younger couples tend to show greater maturity under the stress presented by such a child.

The majority of these studies employ marriage failure as the criterion for assessment of marital stress — deterioration of relationships is mentioned by very few. Walker et al. (1971) found that 26 per cent of mothers and 17.4 per cent of fathers believed that their marriage relationship had deteriorated. One-third of Woodburn's (1973) sample, and 23 per cent of families studied by Richards and McIntosh (1973), reported marriage difficulties. There appeared to be no association between marital disharmony and severity of handicap in the studies by Tew et al. (1974) and Dorner (1975).

2.4.14 Genetic counselling

Since it is well documented (see page 11) that the parents of a spina bifida child face a high risk of having a second handicapped child (in Australia, Field [1972] reports the risk as 1:25), genetic counselling which is adequate in the amount of information given, and in ensuring that the information is clearly understood by all concerned, is an essential service. Genetic counselling to families of a child with spina bifida should be an ongoing process, firstly to the parents who need to be aware of the risks should they wish to continue their family, and later to all their children as they approach adulthood.

The provision of genetic counselling has been subject to criticism in the past, and in many studies a very high proportion of parents report that they received no advice or were completely confused. The proportions are Hare et al. (1966), 60 per cent; Spain (1973), 33 per cent; Richards & McIntosh (1973), 67 per cent.

Kolin et al. (1971) reveal that none of the 5 mothers in their study who expressed the wish to have another child were aware of the risks involved. The authors suggest that this may be due to being inaccurately informed, or it may be that denial of recurrence was necessary to satisfy their need. However, in McAndrew's (1974) study, 89 per cent of parents were satisfied that they had been given adequate information about the risk of producing another defective child.

Receiving wrong information was reported in many instances. It seems that medical practitioners often minimise the risk (Hare et al. 1966; Walker et al. 1971; Richards & McIntosh 1973; Woodburn 1973), and frequently mothers have been advised that the best thing to do was to have another child. Spain (1973) emphasises the view that the area of genetic counselling is a specialist area, and that the general practitioner with very limited contact with spina bifida can hardly be expected to be aware of the risks. Woodburn (1973) reports that very few of her sample of parents attended a genetic-counselling clinic. Parents looked either to the obstetrician, the paediatrician, the general practitioner, the nurse, the social worker or the minister of religion for counselling, and others relied on their own reading of available material to become informed on the question.

In view of the difficulty in understanding and remembering all that is imparted to parents in a counselling session, Woodburn makes the suggestion that parents should not only be given information but also assistance in assimilating it, as well as the opportunity in subsequent counselling sessions to discuss areas that have remained unclear. Woodburn also suggests that it may be necessary to give statistical details in writing, such as the ratio of risk recurrence.

Another aspect of the value of genetic counselling is expounded by Bentovim (1972), who believes that counselling can help parents understand their situation and work through their grief in such a way that neither parent feels the necessity to look for someone or something to blame, thereby lessening the risk of marital and family tension. Not only might the parents endeavour to seek out a cause, especially when there is tension in the home, but the handicapped child may see his or her handicap as the result of actions by his or her parents, or by others in the family, or as a result of his or her own actions.

2.4.15 Family planning

Consequent to the provision of adequate genetic counselling is the need for adequate family planning services, so that parents can act confidently on any decisions that have been made on either limiting or increasing the size of their family. Some studies show that mothers would have welcomed family planning advice, but felt embarrassed about it or were reluctant to seek it (Hare et al. 1966; Freeston 1971; Richards & McIntosh 1973).

Walker et al. (1971) found that of 86 couples, slightly less than 50 per cent agreed that they did not want another child, while 31 per cent wanted to increase their families. However, they also observed that 'fertility following the birth of a spina bifida child appears to be reduced' (p. 470). Record & Armstrong (1975), working in Birmingham, examined the hypothesis that the birth of a malformed child acts as a deterrent to continuing a family if the child survives, and the death of the child frequently acts as an incentive to another pregnancy as parents are anxious to compensate for their loss. While they found some evidence, in the results of the study, that the presence of a malformed child acts as a deterrent to further reproduction, they did not believe that their data fully verified their theory. However, they did find that spina bifida has a slightly greater deterrent effect on having further children than other types of malformations in children.

Anderson & Spain (1977) point out, in a discussion on amniocentesis, that when the mother of a spina bifida child has no moral objection to the termination of a pregnancy, it is an important procedure in ensuring that she bears a healthy baby. But the success of amniocentesis relies heavily on knowing the date of conception, since to be reliable it should be undertaken in the 16th week, and termination of the pregnancy, if decided on but performed much later than the 17th or 18th week, involves considerable risk to the mother. Thus family planning need not be confined to the use of contraceptive techniques, since amniocentesis and termination of pregnancy allows parents to increase the size of their family without fear of producing a second handicapped child.

2.4.16 Effect on child's social relationships

Most spina bifida children studied by Dorner (1976) had good relationships with other members of the family, but some felt that their parents were over-protective. Relationships with siblings were generally reported to be satisfactory, and it was apparent that many siblings made an extra effort to spend time with the handicapped child.

However, the situation with peers was much less satisfactory. Dorner (1975) revealed that 50 per cent of handicapped adolescents were judged (from evidence presented by parents) to be severely socially isolated. But in his 1976 report of interviews with 46 of these adolescents, only 4 (8.7%) claimed they had no close friends; 33 per cent at special schools and over 50 per cent at regular schools had adequate-to-good social relationships.

Social isolation, in that the handicapped child had no friends outside of school, was greatest for those children who attended special schools (57%), compared with only 16.6 per cent of children attending regular schools. Dorner, however, makes the point that it is not necessarily the type of school which is a factor in the degree of social isolation (although nearly 50 per cent of those at residential schools for the physically handicapped were dissatisfied with their school placement), because the level of mobility could be a factor of both special school placement and limited social contact. Only 1 (4.5%) of the studied 22 children with severe mobility problems was not socially isolated, while 41.6 per cent of adolescents with minimal mobility problems were not isolated.

Laurence & Beresford (1975) suggest that important factors in determining the making of friendships are the subjects' childhood and school experiences, the personality of the handicapped person and his or her mobility. Dorner (1976) found that almost all of his sample of 46 adolescents professed an interest in the opposite sex, 65 per cent had thought that they would be able to marry and half of those expected that they would be able to have children. Most were unaware of any risk in a marriage which produced children. Laurence & Beresford (1975) found that to have spina bifida seems to reduce the likelihood of a person marrying. Of their sample of 49 adults, only 22 (44.9%) were married. Of these, 9 women and 9 men had families, but of the 39 pregnancies resulting that had also come to term, 7 were defective (2 spina bifida children and 5 still births, of which 3 were anencephalic) and 5 others were terminated (4 spontaneously and 1 therapeutically). The need for adequate genetic counselling is evident; as is the need for general information about the disorder for young people with spina bifida. Scott, Roberts & Tew (1975) and Dorner (1976) found that relatively few adults with spina bifida knew much about it. Yet, many psychological and emotional problems could be lessened, if not eliminated, if adequate explanations and assistance in understanding their situation were given to affected adolescents.

Incontinence is a major social handicap, but Laurence & Beresford (1975) found that it was a problem that could be coped with without causing undue stress, and without it being a bar to social relationships. Boys fitted with urinary appliances tend to have greatest difficulty in adjusting to their situation. Penile appliances cause greater stress than do urinary diversions (Fulthorpe 1974; Dorner 1975). Fulthorpe concludes that the wearing of a penile appliance often results in the adolescent spina bifida boy becoming acutely and painfully aware of his sexual inadequacy.

Girls fitted with urinary appliances tend to be better adjusted than incontinent girls, who were found to exhibit symptoms of anxiety and withdrawal and had feelings of inferiority and inadequacy (Fulthorpe 1974).

2.4.17 Psychological effects on child

Spina bifida children have a high predisposition to emotional disturbance (Tew 1974). Dorner (1976) found that girls tended to 'feel more misery' than boys; 56 per cent of girls and 19 per cent of boys were frequently miserable. Dorner also found that there is a relationship between misery and social isolation in girls. He draws the conclusion that 'girls are emotionally affected by the consequences of their mobility problems, i.e. social isolation where it occurs, rather than by the lack of mobility itself' (p. 442). Parents are sometimes unaware of the extent of depression felt by their handicapped children, as is evident from Dorner's studies (1975, 1976). Social isolation is the major factor in depression felt by spina bifida children. This emphasises the need for a concentrated effort to remove architectural barriers, and the need for parents to encourage independence in their children. A further major factor causing depression in the teenager is anxiety, and a sense of shame or embarrassment of his or her handicap, particularly incontinence of the bladder (McAndrew 1979). Fear of not being able to establish a satisfying relationship with others tends to increase isolation and loneliness (Anderson & Spain 1977). Ignorance of their disability (Evans, Hickman & Carter 1974; Scott, Roberts & Tew 1975; Dorner 1976) causes considerable stress to many handicapped persons with spina bifida.

The effects of spina bifida on the social and emotional development of a person born with the condition has been examined by relatively few authors. The major areas dealt with have been the effects of hospitalisation in the early years; the effects on social relationships, with particular emphasis on the problem of incontinence; and the psychological effects of the disability. There is, however, a growing interest in the implications of spina bifida for adults who experience the condition, including medical and social considerations centring on pregnancy and obstetric management (Wynn, Mellor & Morewood 1979).

2.4.18 Hospitalisation

It has been assumed that long periods in hospital, and the consequent separation of mother and child, can be the cause of emotional disturbance (Fulthorpe 1974). Freeston (1971) reported that 33 per cent of children in his sample of 4-year-olds had adverse changes in behaviour—disturbed nights, separation anxiety, diminished confidence in walking ability—following hospitalisation, but Tew & Laurence (1976) and Anderson & Spain (1977) report that severe reaction to admission seems rare.

Douglas (1975) and Quinton & Rutter (1976) claim that single hospital admissions lasting a week or less have little effect in the long term, but that repeated hospital admissions are associated with behavioural disturbance in adolescence. These findings were based on large random samples of children, but there has been no replication on any sample of spina bifida children.

2.5 SUMMARY

This chapter has presented a review of literature on medical, social and psycho-educational aspects of spina bifida and hydrocephalus in respect of children and adolescents experiencing these conditions, and their families. The review was undertaken to bring the literature on these aspects together in one source, and assist in application of the findings from previous research to that being reported. No attempt has been made to summarise the research evidence included above, but specific reference will be made to sections of it in later chapters.

CHAPTER 3

MANAGEMENT OF SPINA BIFIDA

(Denise C. Elkins)

The changes in medical treatment of spina bifida and hydrocephalus which have occurred in the past 2 decades suggest that training in all relevant professions needs to be examined to ensure appropriate content is provided. For example, few teachers have any knowledge of spina bifida, yet in Queensland about two-thirds of school age spina bifida children are placed in regular schools. The intention of this chapter is to provide a clear and concise description of the treatment and early management of children with spina bifida, explaining technical terms where possible. It is hoped that this account will provide useful background for teachers and others who work with children with spina bifida and hydrocephalus.

3.1 TREATMENT

3.1.1 The first day

A myelomeningocele lesion is obvious at birth, and the first day of the child's life is crucial. Expert assessment and management are imperative. This often necessitates transferring the child to a major paediatric hospital, and children may need to be brought many hundreds of kilometres for treatment.

Assessment

The assessment includes general health, height and weight. The alimentary, cardiovascular and respiratory systems are examined to locate any other congenital abnormalities. Signs of hydrocephalus are sought and an examination by transillumination of the skull in a dark-room is carried out if the skull is greatly enlarged or asymmetrical. The infant's basic level of neurological function is established by attempting to elicit suck, startle and grasp reflexes, a vigorous cry and lower limb reflexes. The musculoskeletal system is assessed for deformity, reflexes, muscle tone, joint range, sensation and muscle power.

Radiological (X-ray) diagnosis is also used to establish the level of the lesion and reveal other skeletal abnormalities such as curvatures of the spine (scoliosis, kyphosis) and congenital dislocation of the hip. Any aspects that need further investigation, e.g. heart shape, lung fields and gastrointestinal tract, are also pinpointed.

Criteria for selection

The medical team and the parents are faced with a difficult ethical and emotional decision, which frequently has to be made only a matter of hours after the child's birth. The decision to surgically close the lesion and thus place the child on a 'conveyor belt of survival' will affect the lives of the parents and siblings possibly for many years, and the child may have a very poor quality of life, with frequent long-term hospital admissions.

3.1.2 Hydrocephalus

Diagnosis

Diagnosis of hydrocephalus (Brocklehurst 1976) is made clinically by observation of fontanelle ('soft spot') tension and of skull circumference. This measurement is then compared with a chart showing the normal range of head circumference at various ages. Serial measurements over time are also useful to demonstrate that the child's head circumference is increasing more rapidly than normal. In some cases, hydrocephalus can become acute with very little increase in circumference. Air ventriculogram may be used to confirm the diagnosis (Brocklehurst 1976). Computerised axial tomography is likely, with increased availability, to take over from other methods of investigation of ventricular enlargement, as it is very reliable as well as being comfortable for the patient (Brocklehurst 1976).

Treatment

Medical treatment Although 90 per cent of infants with myelomeningocele have some degree of hydrocephalus (Lorber 1961), 10–15 per cent will not need surgery. Various drugs have been used to control hydrocephalus, including acetazolamide and isosorbide. According to Brocklehurst (1976), both of these chemicals have limited use in severe cases, because of side-effects and the necessity for careful monitoring. On the other hand, Lorber (1976) states that since the introduction of isosorbide for the medical treatment of hydrocephalus, far fewer cases have required surgical treatment.

Surgical treatment Surgical shunting procedures are used when hydrocephalus is clinically progressive and usually involve a shunt from the ventricular system to the atrium of the heart or the peritoneal cavity. The Pudenz–Heyer or Spitz–Holter-type valve is used in the neonatal period but usually requires revisions as the child grows (Brocklehurst 1976). Many surgeons use a ventriculo-peritoneal shunt initially, and when normal growth causes blocking, they substitute the ventriculo-atrial shunt. Both the Spitz–Holter and the Pudenz–Heyer shunts have a ventricular catheter which is inserted through a burr-hole under a flap of scalp. The Pudenz–Heyer shunt has a reservoir which sits in the burr-hole and is accessible for diagnosis and therapy if necessary. The cardiac catheter is passed down the internal jugular vein. The Pudenz–Heyer shunt has a non-return valve at the atrium, whereas the Spitz–Holter valve lies subcutaneously near the burr-hole.

3.1.3 Renal complications

About 90 per cent of spina bifida cases have some impairment of bladder function due to the spinal lesion (Forrest 1974).

Causes of bladder dysfunction

The bladder is innervated from low in the spinal column (2nd, 3rd and 4th sacral segments); so, as the lesion is usually higher in the spinal cord, there is upper motor neuron–type bladder dysfunction. The automatic bladder function is similar to that of the newborn child. Spina bifida lesions in the sacral region give rise to lower motor neuron–type symptoms. The bladder is flaccid, and dribbling incontinence occurs.

Later in childhood, the bladder, whether flaccid or spastic initially, becomes atonic with outflow obstruction which, in turn, leads to secondary changes in the urinary tract. Infection is inevitable where there is incomplete emptying. Lorber et al. (1968) found that only 25 per cent of spina bifida cases never develop bladder infections and 25 per cent have continuous urinary infection except when on powerful antibiotics. The effect of reflux is dilation and elongation of the ureters, which, with infection, causes thinning of the renal cortex and hydronephrosis. This can lead to renal failure if there is no intervention.

Management of renal problems

Forrest (1976) has summarised the major aspects of the management of renal problems:

(a) Drainage is promoted by extra fluid intake and the latter must be supervised by parents and teachers until it becomes a habit.

(b) Manual expression is possible in 40 per cent of spina bifida patients, it being necessary to experiment in each case to find the most suitable technique.

(c) Cholinergic drugs are used in patients who have too large a residual volume after manual expression (Ardran et al. 1967).

(d) Catheterisation is used for acute retention in the neonatal period. The indwelling catheter (Forrest 1976) has been used to achieve continence with no serious complications for periods of up to 10 years. However, clean, intermittent self-catherisation is becoming common (Shurtleff 1980; Kupka, Geddes & Carroll 1978).

(e) Surgical procedures are sometimes carried out on the bladder neck and, more recently, on the external sphincter to relieve outflow obstruction. Various reflux-preventing or relieving operations can be carried out at the level of the ureters, including ureteric reimplant and cutaneous ureterostomy. The ileal or colonic loop (Mogg 1967) is the most successful permanent drainage method for urinary incontience or retention, particularly for females. A circle is excised from all layers of the abdominal wall and a stoma is formed for the fitting of an appliance. Noxyflex or Hibitane washouts are used to prevent infection. Recent experience suggests that urinary diversion is not without problems and the procedure has fallen in popularity (Filmer 1980). Some successful reversals of urinary diversions have recently been reported.

(f) Penile appliances for males, with a non-return valve opening to a disposable plastic bag, are relatively successful. The pubic pressure urinal is usually used for younger children and the condom type of sheath is suitable for older children and adults.

(g) Early experimentation with an artificial sphincter has been reported overseas but follow-up studies are not available to permit evaluation of the value of this approach.

3.1.4 Orthopaedic problems

Causes of deformity

The most common cause of orthopaedic deformity in spina bifida is unbalanced muscle action. Because innervation is cut off at a particular segmental level, muscles producing 1 action at a joint will be innervated and the opposing group will be paralysed. Unopposed muscle action produces progressive deformity, because the activated muscle gains an increasing mechanical advantage over its weak opponent (Sharrard 1972, 1973). Bony deformity develops over a long period when the normal range of a joint has been exceeded. Sharrard (1967) shows that bony deformity develops when unopposed muscle does not lengthen as fast as bone because of lack of stimulation from its opponent. Deformities which develop *in utero* affect all the limb structures, including the skin, so they are very rigid. Sharrard (1976) states that deformities due to muscle imbalance are not correctable by passive movement or splinting and that, if improvement is gained, it recurs when the splintage is removed.

It would seem reasonable then to infer that, if the splintage is maintained, as in the continued use of the parapodium to correct foot and other deformities, the foot should remain a suitable shape for weight-bearing without developing pressure areas.

Deformities in flail joints usually develop after birth and are associated with fibrosis in the tendon sheaths and joint capsules. These deformities are responsive to passive movement and splinting.

Because of the lack of sensation, pathological fractures and slipped epiphyses can go undetected, and they may result in some degree of deformity. Deformities due to absence of fibula, foot, ribs or sacrum may occur, and kyphosis of the lumbar spine is frequently seen in association with the spina bifida lesion.

Sharrard (1976) also makes special mention of recurrent deformity:

> If a deformity has been corrected operatively in a part of the limb that appears to be completely paralysed . . . the recurrence of the deformity in spite of maintenance of passive movements of the joint should give rise to suspicion that there may be autonomous or semi-reflex activity in the muscle which is immune to detection by clinical means. In such an instance, electrical stimulation will often reveal activity in the muscle responsible for the recurrent deformity. (p. 86).

Correction of deformity

Progressive deformity is an indication for surgery and this can be commenced by about 6 months of age. Correction of tendon length in combination with muscle-balancing transplants is often sufficient, although sometimes more than 1 operation is necessary. Ideally the deformity should be corrected by the time the child is 2 years old so that appropriate bracing can be applied and walking instruction can begin.

Between the ages of 2 and 5 years, osteotomy (corrective bone surgery) is sometimes necessary when soft-tissue corrections have failed. Arthrodesis (surgical joint fusion), usually to stabilise joints at the ankle or foot, is usually not attempted before the age of 12 years. This procedure may allow calipers to be discarded. Menelaus (1980) gives a valuable account of the issues which arise in the correction of spinal deformities in children with myelodysplasia.

In recent years, more consideration is being given to the ultimate goals of orthopaedic surgery. The aim is to improve function to allow independence and peer interaction with a minimum of surgery and hospitalisation.

Complications of sensory loss

Pressure sores These usually occur in an area of anaesthetic skin overlying a bony prominence. The most common sites are the plantar surface of the foot, the ischial tuberosities (buttocks), the outer sides of the hips or the front of the knees.

The prevention of fixed deformity in the foot is very important in avoiding pressure sores on the sole. The more active the child and the better the general level of innervation to the lower limbs, the more likelihood there is for pressure sores to develop, because of the greater stresses on the anaesthetic skin of the feet. The parents or the older spina bifida child must be taught to look for areas of excessive redness on the feet, so that pressure sores can be prevented by adapting footwear to spread the pressure evenly over the sole. Fleecy-lined boots in cold weather prevent chilblains, as well as spreading pressure.

Ischial sores occur in severely paralysed children who are confined to wheelchairs. The child must be taught to alter the distribution of weight on the buttocks regularly, and where possible, calipers can be used to allow the child to stand for several periods during the day.

Pressure sores on the knees occur in younger children as the results of crawling or dragging themselves in the prone position. Calipers to produce upright weight-bearing will usually allow these to heal.

Corrective plaster casts and calipers can also cause pressure ulceration if not sufficiently padded or if badly applied or designed.

Spontanecus fracture Pathological fractures are liable to occur in the bones of the lower limbs (James 1970), and there is a relationship between the most likely site of fracture and the level of the lesion in the spine. In limbs with complete paralysis, fractures may occur at any part of the femur or tibia. If there is innervation down to lumbar 3, the commonest site of fracture is the lower end of femur or upper tibia. If innervation exists to L5 the fracture is more likely to occur at the lower end of the tibia or in the foot. There may also be metabolic causes for bone fragility, such as renal rickets due to disturbance of vitamin D metabolism or abnormal utilisation of vitamin C, which can cause epiphyseal displacements (McKibbin & Porter 1967). The treatment is usually minimal, with crepe bandages to maintain alignment.

Charcot joints Degeneration in the joints occurs most often in children with minimal paralysis who are able to be active but who have sensory loss. For this reason, these children should avoid active sports and particularly contact sports. The most common site is at the subtaloid joint below the ankle, secondary to pathological fracture of the calcaneum and talus bones in the heel.

3.2 PHYSIOTHERAPY MANAGEMENT

3.2.1 Assessment

Neonatal

In some centres, the physiotherapist carries out an initial assessment a short time after the birth of the infant with spina bifida. This assessment becomes part of the information on which the decision whether or not to close the lesion is based. The infant's general level of neurological functioning and response to handling are observed, taking into account the child's level of wakefulness. Sensation is tested by stimulation of the areas supplied by a particular nerve root where there is little or no overlapping with other nerve roots. According to Holgate (1970), the following reflexes have a fair degree of reliability in the first 2 days of life:

knee jerk
babinski sign
crossed extension reflex
withdrawal reflex
ankle jerk
grasp reflex
finger extension reflex
stretch reflex of elbow flexors
anal reflex

Neurological assessment in the neonate is difficult. The leison is often an upper and lower motor neurone mixture producing bizarre patterns of movement. It is important to realise that stimulation does not indicate cortical control and cortically evoked responses. Therefore, it is necessary to determine whether the movement is voluntary or reflex.

Abnormalities in muscle power in the upper limbs are found less frequently and can be better assessed later. If, however, the myelomeningocele is in the cervical region, or brain damage is suspected, a general sensory and muscle assessment can be made before the leison is closed. A useful guide to the potential capabilities of children due to the neurosegmental level of the lesion is given by Kupka, Geddes & Carroll (1978).

One week to 1 month

The infant can be reassessed 1 week post-operatively and again at 1 month. Charting will show the effects of the surgical closure of the lesion, and whether there is deterioration, maintenance or improvement in muscle power. Further reflexes and signs which are useful at this stage are:

- walking reflex (present until 3 weeks)
- supine suspension — note asymmetry
- asymmetrical tonic neck reflex
- ankle colonus
- prone suspension — note asymetry
- placing response

In prone lying, with the buttocks held down, there should be some resistance to flexion of the knee.

As well as reassessing the lower limbs, muscle charting of the upper limbs is attempted at about 1 month.

Six months

With the insertion of a shunt to control the hydrocephalus, most of these children have lost their primitive reflexes by the age of 6 months and the innervated muscles are coming under cortical control.

Three years

By 3 years of age the children with normal intelligence can co-operate to give a sensory assessment and to produce active contraction of the various muscle groups on command.

3.2.2 Treatment

Early treatment

Passive stretching Daily stretches are carried out to maintain full range of movement in the legs and arms and to assist in the correction of deformity.

Where there is restriction of range, the joint should be held at the full extent of range for 20 seconds to avoid eliciting any stretch reflex. Great care must be taken not to damage the epiphyses or cause fractures in poorly ossified bones, so the hands must support as closely to the joint being stretched as possible and all stretching must be gentle.

Strapping The Robert Jones method of strapping for equinovarus feet is used, with several modifications. Because of lack of sensation, poor blood supply and sensitive skin, 25 mm-wide sticking-plaster is used instead of zinc oxide plaster. This also allows for manipulations while the strapping is in place. The knee is not included in the strapping, as the child is not usually able to kick to apply an extra corrective force. Great care must be taken not to cut off the circulation. Full correction is not attempted with strapping.

Positioning The infant should be placed in the prone position for part of each day to facilitate activity in the hip and back extensors. If, after a shunt has been inserted, the baby habitually turns away from the valve side when lying in the supine position, the prone position is beneficial, because the baby will turn to the valve side to avoid pressure on the valve. If the hip adductors are tight, a double napkin will hold them in a position of some abduction.

von-Rosen splints These are used during the day only so that any pressure on the skin is relieved overnight. Although hip surgery is usually still necessary at about 18 months to correct muscle imbalance, the splinting can minimise the extent of the dislocation of the hip.

4.3 A DESCRIPTION OF THE SPINA BIFIDA AND HYDROCEPHALIC POPULATION IN QUEENSLAND

4.3.1 General characteristics

The age range of the 240 children and adults was from 4 months to 22 years 9 months, with a mean age of 8 years 2 months. Of these subjects, 117 (48.7%) were male and 123 (51.3%) were female (Table 4.2).

A broad grouping of the disabilities experienced by the research population produced the diagnostic information in Table 4.3. The data have been organised around the occurrence of spina bifida with or without hydrocephalus, except that subjects experiencing hydrocephalus have been further subdivided into those who have been surgically fitted with a valve (shunt) to control the hydrocephalus and those without a valve.

Table 4.2: **Age and sex of the research population(*a*)**

	Male		*Female*		*Total group*	
Age groups	*No.*	*%*	*No.*	*%*	*No.*	*%*
Birth to 4 yrs 11 mos	26	35.1	48	64.9	74	(30.8)
5 yrs 0 mos to 9 yrs 11 mos	46	54.8	38	45.2	84	(35.0)
10 yrs 0 mos to 14 yrs 11 mos	31	57.4	23	42.6	54	(22.5)
15 yrs 0 mos to 19 yrs 11 mos	11	45.8	13	54.2	24	(10.0)
20 yrs 0 mos to 24 yrs 11 mos	3	75.0	1	25.0	4	(1.7)
Totals	117	(48.7)	123	(51.3)	240	(100.0)

(*a*) Percentages given are for each age group, except those in parentheses which are for the total group.

Table 4.3: **Diagnostic classification of the total research population**

			Per cent			
Diagnosis	*No. of subjects*		*Valid cases*		*Total group*	
Spina bifida only	40	157	19.0	74.7	16.7	65.4
Spina bifida and hydrocephalus, with shunt	99		47.1		41.2	
Spina bifida and hydrocephalus, without shunt	18		8.6		7.5	
Hydrocephalus only, with shunt	33	53	15.7	25.2	13.8	22.1
Hydrocephalus only, without shunt	20		9.5		8.3	
Missing data(*a*)	30				12.5	
Totals	240		100.0		100.0	

(*a*) The missing data reported here and elsewhere in this chapter includes cases for whom names and limited information were obtained. For completeness, all are included in the total research population and appropriate tables, but comprehensive data were not always available. The extent of variability of the data available from the many reference sources used is evident from the missing-data entries in the tables of this chapter.

Of the 157 cases of identified spina bifida, 25.5 per cent were experiencing spina bifida only, 63.0 per cent also had hydrocephalus which had been treated by insertion of a valve, and 11.5 per cent had hydrocephalus but had not been treated by use of that procedure. There were 53 cases experiencing only hydrocephalus; 62.3 per cent and 37.7 per cent of these, respectively, had been fitted with a valve or had not been so treated.

The extent of mobility in this population is useful to indicate the degree of handicap experienced by them:

> Of the cases for whom the information was available, 57.4 per cent were independent in walking with or without use of a walking-aid, 23.4 per cent were dependent and 10.5 per cent were bedfast. Some 8.7 per cent were too young to be assessed as to mobility.

4.3.2 Educational and residential data

As the age range of the subjects was from birth through the school-age years and into the early 20s, some subjects were of an age for which educational placement was not appropriate. In this respect, the study included 45 children and infants under pre-school age (18.7 per cent of the total group) and a number of adolescents and young adults who had left school. It also included 30 subjects (12.5 per cent) in long-term residence who, with 1 exception, resided in Department of Health long-term hospital or residential care.

Table 4.4 gives details of educational and residential placement of the total research population. It will be observed that the largest groups were the children in regular primary and special schools. If only subjects for whom educational or residential placement is known are taken into account, 20.2 per cent were under 4 years of age, 13.5 per cent were living in long-term care, 23.8 per cent were in regular primary schools and 22.0 per cent were in special schools.

If this information is reorganised to be comparable with the preliminary information given in Table 1.2, it will be noted that, of the infants and children of school age (208 subjects), 36.5 per cent were in regular schools or pre-schools, 30.8 per cent were in special schools or special pre-schools, 21.6 per cent were too young for school attendance and 11.1 per cent were not enrolled in educational programs. When the school-attending group only is taken into consideration (132 subjects), 57.6 per cent were enrolled in regular schools and pre-schools and 42.4 per cent were in special schools and special pre-schools.

The study was concerned with children and young adults experiencing spina bifida and/or hydrocephalus throughout Queensland. Place of family residence was therefore important, and Table 4.5 sets out the geographical distribution of the families of the subjects based on 3 major residential categories: The Brisbane metropolitan area, other urban areas (cities and towns with populations in excess of 10,000), and rural districts. The indicated distribution of families shows, as would be expected, the largest group living in the metropolitan area, with smaller proportions living in other urban and rural locations. The comparative figures for all Queensland families show the research group of families to be located proportionately more in urban than rural areas.

Family residence was not the place of usual residence for 75 subjects (31.25 per cent of the total group). Because of the isolated geographical location of some families, with the resultant need for residential school placement, and because some subjects who were severely multiply handicapped required a level of care not always possible at home, these 75 subjects lived in residential school or long-term care.

Table 4.4: **Educational/residential placement of the total research population: by sex**

Type of educational/ residential placement	*Males*		*Females*		*Total group*	
	No.	*%*	*No.*	*%*	*No.*	*%*
Not attending educational programs						
Under 4 years						
At home	11	4.6	27	11.3	38	15.8
In long-term residential care	4	1.7	3	1.3	7	2.9
Four (4) years and over						
At home			1	0.4	1	0.4
In long-term residential care	13	5.4	9	3.7	22	9.2
Attending school or pre-school						
Regular pre-school	8	3.3	5	2.1	13	5.4
Special pre-school	4	1.7	11	4.6	15	6.3
Regular primary school	27	11.2	26	10.8	53	22.1
Special school	27	11.2	22	9.2	49	20.4
Regular secondary school	5	2.1	5	2.1	10	4.2
Post-school						
Living at home or in community	9	3.7	5	2.1	14	5.8
Living in long-term residential care			1	0.4	1	0.4
No information on educational program	9	3.7	8	3.3	17	7.1
TOTALS	117	48.7	123	51.3	240	100.0

Table 4.5: **Geographical location of family residence**

Location	*No. of families*	*Per cent of total group*	*Per cent for total Queensland families(a)*
Metropolitan (Brisbane)	115	47.9	44.2
Other urban areas	69	28.8	20.9
Rural areas	47	19.6	34.9
Missing data	9	3.8	
Totals	240	100.0	100.0

(*a*) Based on data made available by the Australian Bureau of Statistics from the 1976 census.

Details of usual place of living are set out in Table 4.6. It will be noted that 62.5 per cent of the total group were living at home. Those children in residential schools had variable access to their homes, visits ranging from weekly to annually, usually depending on geographical distance. Of those children in long-term care, the majority were living in centres for young profoundly handicapped children, which are the 3 locations listed last within the table.

Table 4.6: **Usual place of residence for the total research population**

Usual place of residence	*No. of subjects*		*Per cent of total group*	
Living at home	150		62.5	
Residential school				
At home weekly	12	41	5.0	17.1
At home once each term	16		6.7	
At home once each year	13		5.4	
Long-term residence				
Challinor Centre	7	34	2.9	14.1
Basil Stafford Centre	1		0.4	
W. R. Black Home	6		2.5	
Prince Charles Hospital Unit	11		4.6	
Maryborough Hospital Unit	7		2.9	
Rockhampton Hospital Unit	2		0.8	
Missing data	15		6.3	
Totals	240		100.0	

4.3.3 Family data

The majority of the subjects were 1st- or 2nd-born children, with 38 per cent of the subjects for whom data were available being 1st-born and 29 per cent 2nd-born children. The figures presented are generally comparable to those reported in other research studies.

Family size was determined during the interviews conducted with 130 families, and by consulting school and institution records for a further 62 families. The data relate to family size as at mid-1977. The largest group of subjects (64, or 33%) came from families with 2 children. Nearly 80 per cent of the families had from 2 to 4 children, while only 15 per cent of families had 1 child at the time of data collection.

Table 4.7 indicates that 85.3 per cent of the families for whom data on the parental status of families were available (218) were 2-parent families, and some 10 per cent were single-parent families. The small numbers of children in State care will be noted, as will the 5 children who lived with adoptive or foster parents.

Table 4.7: **Parental status of the families of the 240 subjects**

Parental status of families	*No. of families*	*Per cent*	
		Valid cases	*Total group*
Two parent family	186	85.3	77.5
Single parent (mother)	18	8.3	7.5
Single parent (father)	4	1.8	1.7
Adoptive parents	1	0.4	0.4
Foster parents	4	1.8	1.7
Child in State care	5	2.3	2.1
Missing data	22		9.2
Totals	240	100.0	100.0

Instruction to the parents When the infant is first discharged from hospital, the parents will need extensive instruction from several members of the medical team. Ideally the parents will have learned the basics in nursing-care, feeding, bladder expression and observation of the valve during visits to the hospital. It is also to be hoped that the social worker will have been able to discuss any social or financial problems and to make arrangements for help where possible. The parents will certainly have had discussion with the paediatrician in charge of the infant but will probably require further reassurance and advice at this stage. The physiotherapist, therefore, should spread instruction to the parents over several sessions and should give them a typed list to take home.

The parents should perform each segment of the home program in front of the physiotherapist, following the demonstration and explanation. This allows correction where necessary. The physiotherapists should also give advice about how often the program should be carried out and how often inspection of the skin for pressure areas and lack of circulation should be undertaken.

A shunt may block and it is necessary for people working with children to recognise signs of this if it should arise. The signs of intercranial pressure are irritability, drowsiness, not eating, vomiting, squint or coma.

Problems of locomotion

The factors affecting locomotion in spina bifida children are:

(a) The level and nature of innervation of the lower limbs
(b) The pressence of hydrocephalus
(c) The presence of deformity and feasibility of bracing
(d) Intelligence, motivation and personality

If there is good innervation from the lumbar segments, bracing will only be needed below the knee. If the leison is higher than lumbar 4, bracing at the hip, as well, will be needed. The trunk muscles are usually able to elevate the pelvis to allow alternate limbs to clear the ground.

Hydrocephalus and low intelligence make independent walking much more difficult. According to Brocklehurst (1976, p. 120), 'hydrocephalus disturbs balance and spatial orientation', presumably because of the CSF pressure and the malformations in the cerebellum and brain stem. Even if there is very little paralysis in lower limbs, a child with hydrocephalus has difficulty in balancing until he or she is 4–5 years old and is very frightened of attempting to walk across a space unless touching someone's hand or some means of guidance by the upper limbs is available. It is thought that the increased head size and weight add to the difficulties in locomotion, and while they present problems in the developmental sequence leading up to walking, Wallace (1973) found that moderate increase in occipitofrontal circumference was not in itself sufficient to interfere with mobility. If intelligence is low, the child will have difficulty understanding how to use limbs and walking-aids. Because of brain damage, he or she may have the added disadvantages of lack of motivation and distractability (Laurence & Coats 1967).

Preparation for walking

Tizard (1968) states that all handicapped children have difficulty in passing developmental milestones, not only because of their handicaps but also because they have limited opportunities to explore the environment, to enjoy a normal range of experience and to play with other children and their parents. Play is regarded as an important developmental factor and many of these children need to be taught to play. A spina bifida child's milestones will almost certainly be delayed, but normal starting-times are given in parentheses (Holgate 1970) in the sequence that follows.

Stockmeyer (1967), in her interpretation of treatment of neuromuscular dysfunction by Rood, defines stability as the motor function which fixes parts of the body for weight-bearing. Stability is developed in a cervicocaudal direction, the neck achieving stability first and then the trunk and upper extremities, which coincidently develop the ability to support the trunk in a horizontal position. The lower trunk and legs lag behind in the achievement of mobility. With the spina bifida child, the neck, upper limb and trunk components of the developmental sequence discussed by Rood (1962) can be mastered, but because of, in many cases, almost total loss of innervation to the lower limbs, normal patterns can only be developed to a limited degree. Stockmeyer (1967) also gives a wealth of ideas regarding equipment and toys which can be used to stimulate a particular desired response.

Holgate (1970) also uses a program following the normal developmental sequence:

(a) *Head control* (4 weeks). Prone lying will encourage the infant to lift the head to look around. Lifting the child to sitting from the supine position will encourage activity in the anterior neck muscles (6–8 weeks). Supported sitting, swaying the infant off perpendicular, will encourage head control and co-ordination of neck muscles (20 weeks). Control is often hampered by the heaviness of the head.

(b) *Sitting* (28 weeks). This is attempted with the weight of the body forward on the arms to support weak back muscles. Adapted chairs can be used to encourage sitting in gentle stages. The back of the chair can be adjusted at increasing angles from the horizontal and foam packing is used to support the head and kyphotic back if necessary.

(c) *Rolling* (6–7 months). Facilitation of rolling at hip level is often necessary until the child's muscle power at the shoulders and trunk has developed sufficiently to allow him or her to carry the movement through. At this stage it should be practised as a game.

(d) *Crawling* (8 months). Most spina bifida babies learn to push themselves backwards with their arms, to attain the crawling position, unaided. However, they will need help and encouragement to move forward. The arms will, of necessity, do most of the work, which strengthens them for their considerable future tasks. Even children with high lumbar lesions can learn to balance on all fours and to crawl with the aid of slings and, later, with a 'crawler' which consists of a padded board on castors. The child will need careful skin protection.

(e) *Lying to sitting*. Children may need coaching to lift the weight of the trunk onto the forearm, in side lying, then to push with the other arm to raise the body to sitting. It may be necessary for children to pull themselves up on the side of the cot until this can be mastered without aids.

(f) *Standing* (9 months). In the spina bifida child, with encouragement, standing may occur between 18 and 24 months. Baby 'walkers' can be used in selected cases when head control and back muscles are good. Calipers or a parapodium are indicated when the child attempts to pull to standing. The child should then stand, for several periods each day, in a waist-height table with a hole in the centre while learning standing balance on anaesthetic limbs. Kneel-standing is also important if there is some power at the hip joint.

(g) *Pre-walking exercises*. The following exercises are valuable prior to the walking stage:

  (i) Press-ups, with hip support initially
  (ii) Balance work, in a prone kneeling position
  (iii) Raising body weight off the ground, in a sitting position, using the arms

(iv) Wheelbarrows, with hip support
(v) Arm support, sitting on a rocker board
(vi) Sitting on a trampoline, bouncing up and down using the arms
(vii) Sit-ups, with stabilisation of the pelvis

(h) *Walking training.* Tremendous effort and time goes into teaching the spina bifida child to walk. The advantages over a wheelchair existence are:
   (i) independence of movement so that as the child reaches adulthood, he or she does not have to be lifted;
   (ii) improvement in general health and outlook on life;
   (iii) freer drainage of the kidneys;
   (iv) less likelihood of pathological fractures in lower limbs;
   (v) increased ventilation of lungs, so less tendency to chest infections.

Double calipers, and trunk support with hinges allowing 20 degrees of abduction and adduction and a small free range of flexion and extension, make it possible for even a severely paralysed child to walk, with an alternate gait, using a walking-frame and, later, elbow crutches (Herzog & Sharrard 1966). Less severely paralysed children may be able to discard the hip support when walking balance is well established and to progress with gradually less apparatus.

Many children can progress much more rapidly with a swing-through gait and crutches. This may allow them to participate in sport and be very good for their morale. It should not be discouraged, therefore, but the child should be taught alternate lower limb–walking as well.

As the child approaches puberty, it becomes very difficult to sustain walking ability if paralysis is severe. The increased size and the tendency to obesity, without commensurate increase in muscle power in the legs, tend to make the child more dependent on a wheelchair, so if the child is confined to a wheelchair, an attempt to walk should be made once a day to avoid the above problems. Hewson (1976) defines useful independence as the ability of the subject to walk 25 metres and to sit on, and rise from, a chair.

Special calipers have been devised to aid independent walking, particularly in children with good flexor power but no extensors of the hip. The use of a link between the 2 limbs with a gearbox such that flexion of 1 limb produces extension of the opposite limb (along the lines of the myostatic reflex arc of the nervous system) has a useful place in children with paralysis below the 2nd or 3rd lumbar segment.

The use of a wheelchair by children with myelodysplasia may be encouraged even where walking is possible, because wheelchair use may increase functional mobility in school or community settings. Considerable attention should be paid to their attainment of satisfying lives with high levels of active participation among their peers, rather than over-reliance on narrow orthopaedic criteria for management.

3.3 SUMMARY

While much remains to be learned about the management of children with spina bifida, advances in surgical techniques have reached a stage where a fairly stable picture has emerged with respect to the early treatment of these children. In many respects the new frontier in the care of spina bifida children has shifted to the school-age and adolescent period. Here, subtle problems of adjustment and specific difficulties are beginning to be recognised (Anderson 1976*a*, 1976*b*). Since they are now the second largest group of physically handicapped children, it is imperative that researchers from a variety of disciplines give their attention to studying children with spina bifida as they progress through the school years to adulthood. Further sharing of expertise by the various professionals who can contribute to the management of children with spina bifida can allow truly transdisciplinary services to be developed.

CHAPTER 4

A STUDY OF SPINA BIFIDA AND HYDROCEPHALUS IN QUEENSLAND

4.1 SUBJECTS

As indicated in Chapter 1, this report is based largely on a major study of Queensland children with spina bifida and hydrocephalus, especially those of school age. The total research population identified numbered 240 children and young adults[1]. This chapter presents a basic description of some of the characteristics of this total group of subjects and their families.

During the period of data collection for the study, which extended throughout 1977, 240 children, adolescents and adults with presenting spina bifida and/or hydrocephalus were identified in Queensland. These were mostly ascertained from case lists held by the State Education Department and the Spina Bifida Association of Queensland, but also through the interest of schools and parents, and efforts by the staff of Regional Guidance Offices. In addition, the North Queensland Society for Crippled Children made its case records available, and checks were made on children in the care of the Montrose Home (Queensland Society for Crippled Children), the Xavier Hospital for Children, and other community groups. A significant group in the total research population was also identified through the records of the Queensland Health Department, essentially children and adults in long-term residential care.

4.2 PROCEDURES

Following identification of the subjects, the procedures employed in the study were as given in Table 4.1, listed on the basis of the major data areas which were pursued.

Table 4.1: **An overview of research procedures**

Data areas	*Procedures*
Family–social data	Parent interviews based on a structured questionnaire
Psycho-educational data	School administrators questionnaire
	Teachers questionnaires
	Pre-school
	Primary and special schools
	Secondary school
	Home-room teachers
	Subject teachers
	Psychometric and educational tests
	Observation studies
	Sociometric studies
Educational–vocational data	Interviews with school-leavers

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[1] A further 17 subjects are listed in our records who were found to live in other States. These cases were not included in the data for this study.

differences between the diagnoses of this group of 130 subjects and the total research population (Table 4.2) can be noted. Basically the proportion of subjects with spina bifida alone is higher, and that with hydrocephalus alone is lower in the group who were in residential care, (there was a higher proportion of subjects with hydrocephalus alone).

The age, sex and diagnosis of the 130 subjects are given comparatively in Table 5.1, with the addition of a differentiation between those subjects experiencing hydrocephalus and who had, or did not have, a shunt fitted to control their hydrocephalus. The small number (7) of those hydrocephalic children who were without a shunt will be noted, representing 5.4 per cent of the total cases in the group, or 7 per cent of all those with hydrocephalus.

In this group of 130 children, 35.4 per cent were 1st-born and 27.7 per cent 2nd-born children, making a total of 63.1 per cent either 1st- or 2nd-born children. Eighty per cent of the group were 1st-, 2nd- or 3rd-born children. In addition, 3.8 per cent of the children were born at the 6th or a later place in the family. In general, these findings follow the reported trends from research in other countries and are very similar to the data reported for the total group of 240 subjects (Chapter 4).

In respect to size of family, at the time of interview, 11.5 per cent were sole children, while 34.7 per cent were members of a family with 2 children. Ninety per cent of the children were in families ranging up to and including 4 children. Some 10 per cent were in families of 5 children or more.

Of the 114 children in this group who were experiencing spina bifida, 97.3 per cent (111) had had the lesion associated with that condition closed. Two children did not require surgery and 1 child had a lesion which had not been repaired. Of the 111 cases, 91 children (82.0%) had undergone surgery for the condition when they were less than 1 month old (Table 5.2) and 78 (70.3%) of the children had undergone surgical intervention to close the lesion within the 1st week after birth.

Table 5.2: **Children with spina bifida: age at which surgery to close lesion was performed**

Age at time of surgery	*No. of children*		*Per cent of valid cases*	
Under 1 month	91	105	82.0	94.6
1–2 months	3		2.7	
3–6 months	11		9.9	
7–9 months	3		2.7	
Over 9 months	2		1.8	
Age of closure not known	1		.9	
Not applicable	3		–	
Totals	114		100.0	

Altogether, over 94 per cent of the children had the lesion closed by 6 months of age. Of the 2 children over 9 months of age when surgery was performed, 1 was aged 1 year 10 months and the other was aged 3 years 10 months at the time of surgical intervention.

There were 95 children in this group of 130 who had experienced hydrocephalus. Of these, 89 (93.7%) had had a shunt inserted and 5 had not. The status of 1 child in this respect could not be determined (Table 5.3). Surgical intervention for shunt insertion to ameliorate the effects of hydrocephalus typically took place a few months later than for closure of the lesion associated with spina bifida. It was not until 6 months of age that 83 per cent (74 children) of this group had received a shunt, while only some 94 per cent had undergone this surgery before the age of one. A small number of cases in the group did not receive initial surgery associated with hydrocephalus until after the age of one.

Table 5.3: **Children with hydrocephalus: age at which initial surgery to insert shunt was performed**

	No. of children		*Per cent of valid cases*	
Under 1 month	39	74	43.8	83.1
1-2 months	13		14.6	
3-6 months	22		24.7	
7-9 months	5		5.6	
10-12 months	4		4.5	
1-5 years	4		4.5	
Over 5 years	2		2.3	
Not applicable	6		–	
Totals	95		100.0	

Table 5.4: **Place of family residence at time of child's birth**

Residential location	*No. of families*		*Per cent of group*	
Metropolitan				
Brisbane	49		37.7	43.1
Greater Brisbane	7		5.4	
Other urban				
Provincial cities	43		33.1	
Rural				
Country towns	16	21	12.3	16.1
Rural districts	5		3.8	
Other locations				
Metropolitan interstate	3	9	2.3	6.9
Rural interstate	1		0.8	
Overseas	5		3.8	
Missing data	1		0.8	
Totals	130		100.0	

5.2 THE FAMILIES

The families of the 130 children and adolescents resided in all major regions of the State, being located in the Brisbane metropolitan area (51%), other urban areas (39%) and rural areas (10%). This distribution of families is fairly uncharacteristic of the distribution of the Queensland population generally, and rural families in particular are under-represented in this group, compared with the total research population.

The extent of change in family residence can be gauged by comparing the above percentages -- referring to place of living when interviewed — with those in Table 5.4, which gives the family place of residence at the time of the birth of the handicapped child. As might be expected, the major trend in change of residence seems to have been from rural areas to provincial cities to the metropolitan region (Table 5.5). Some 7 per cent of the families had moved into Queensland, about equally from interstate and overseas.

Table 5.5: **Change in place of family residence**

	Per cent of families	
Residential location	*At time of child's birth*	*At time of interview*
Metropolitan	45.4	51.0
Other urban	33.1	39.0
Rural	16.9	10.0
Other locations and missing data	4.6	-
Totals	100.0	100.0

The age of both parents at the time of their child's birth was determined during the interview (Table 5.6). It will be observed that fathers tended to be older than the mothers, although both groups had a modal age between 26 and 30 years. The extremes of the age distributions are perhaps more significant, since there are a few teenage mothers and fathers and 16 parents were more than 40 years old when their handicapped child was born.

The modal ages of parents at the time of interview were naturally greater, being within the range of 31–35 years for the mothers and 36–40 years for the fathers. Almost 6 per cent of parents were aged more than 50 years when the interviews were conducted.

Parental occupations at the time of interview are presented in Table 5.7. They are given on the basis of 8 categories which correspond to the occupational classification employed by Broom, Jones & Zubrycki (1965) and are linked to the Index of Occupations of the Commonwealth Bureau of Census and Statistics.

Seventy-seven per cent of the mothers were not engaged in employment outside the home, those who were, being employed in the unskilled occupations of categories I and II (10%), in clerical and other skilled occupations (7%) and professional positions (4%). The fathers were distributed across most occupational groups, with 49 per cent employed in skilled trades and 31 per cent in managerial and professional positions. Nearly 15 per cent were employed in the occupations designated in Categories I and II.

Table 5.6: **Age of parents at time of child's birth and at interview**

Age ranges (in years)	*Mothers* *No.*	*%*	*Fathers* *No.*	*%*
At birth				
< 20	9	6.9	2	1.5
21 to 25	43	33.1	28	21.5
26 to 30	50	38.5	53	40.8
31 to 35	18	13.8	25	19.2
36 to 40	4	3.1	12	9.3
41 to 45	4	3.1	4	3.1
46 to 50	–	–	–	–
51 to 55	–	–	2	1.5
Missing data	2	1.5	4	2.1
Totals	130	100.0	130	100.0
At interview				
< 20	3	2.3	–	–
21 to 25	12	9.3	7	5.4
26 to 30	28	21.5	30	23.1
31 to 35	36	27.7	24	18.5
36 to 40	27	20.8	30	23.1
41 to 45	9	6.9	16	12.3
46 to 50	8	6.2	7	5.3
51 to 55	5	3.8	10	7.6
Missing data	2	1.5	6	4.5
Totals	130	100.0	130	100.0

Table 5.7: **Occupations of parents of families interviewed**

Occupations *Categories*	*Description*	*Mothers* *No.*	*%*	*Fathers* *No.*	*%*
VI	Professional	5	3.8	14	10.8
V	Managerial			26	20.0
IV	Clerical	8	6.2	16	12.3
III	Craftsmen/Foremen	1	0.8	48	36.9
II	Shop assistants	2	1.5	7	5.4
I	Personal, domestic and service workers	11	8.5	12	9.3
O	Home duties	100	76.9		
	Pensioners and unemployed	1	0.8	2	1.5
Missing data		2	1.5	5	3.8
Totals		130	100.0	130	100.0

Table 4.8: **Socio-economic categories***(a)* **of families (based on father's occupation if supporting the family)**

Categories	*Description*	*No. of families*	*Per cent* *Valid cases*	*Per cent* *Total group*
VI	Professional	24	12.8	10.0
V	Managerial	36	19.1	15.0
IV	Clerical workers	20	10.6	8.3
III	Craftsmen and foremen	56	29.8	23.3
II	Shop assistants	9	4.8	3.8
I	Personal domestic and service workers	27	14.4	11.3
O	Home duties	5	2.7	2.1
	Pensioners, unemployed	11	5.9	4.6
	Missing data	52		21.7
	Total	240	100.0	100.0
V–VI	Professional and managerial	60	31.9	25.0
III–IV	Clerical workers and craftsmen etc.	76	40.4	31.7
I–II	Shop assistants, personal workers etc.	36	19.2	15.0
O	Home duties, pensioners etc	16	8.6	6.6
	Missing data	52		21.7
	Totals	240	100.0	100.0

(*a*) Socio-economic categories are based on the classification by Broom, Jones & Zubrycki (1968). It is linked to the Index of Occupations of the Commonwealth Bureau of Census and Statistics.

Table 4.9: **Comparison of socio-economic categories of families studied and Queensland families generally**

Categories	*Description*	*Per cent of families* *This study (n = 188)*	*Per cent of families* *Queensland(a)*
VI	Professional	12.8	8.3
V	Managerial	19.1	8.1
IV	Clerical workers	10.6	15.4
III	Craftsmen and foremen	29.8	50.8
II	Shop assistants	4.8	8.3
I	Personal domestic and service workers	14.4	9.1
O	Home duties, pensioners, unemployed	5.9	–
	Totals	100.0	100.0

(*a*) Based on male occupational data made available by the Australian Bureau of Statistics from the 1976 census.

The occurrence of spina bifida and hydrocephalus in this research population was spread over families of all socio-economic levels, levels being estimated from the occupation of the father where he was supporting the family, otherwise from the occupation of the mother or guardian. Based on the valid cases, 31.9 per cent of those supporting the families held professional or managerial positions, 40.4 per cent were clerical workers or craftsmen, and 19.2 per cent were employed as shop assistants or personal and service workers (Table 4.8). Only 8.6 per cent were pensioners, unemployed or undertaking home duties. A broad comparison of these figures with those reported in Chapter 2 from other research studies suggests that the upper category occupations are over-represented in this research population, with a resulting decrease in numbers in middle category occupations, while the incidence in Groups O–II is fairly comparable.

Table 4.9 compares the detailed figures in Table 4.8 with those for the Queensland population in 1977. It will be noted that the families of the subjects in the employed research population differ significantly from the Queensland population ($x^2 = 63.92$; $p = <0.001$; Degrees of freedom = 5), and in similar ways to those detailed above.

4.4 SUMMARY

This chapter has described the total research group of children, adolescents and adults in terms of their age, sex, diagnosis, mobility, position in family, and educational/residential placement and reported some characteristics of the families in the research group. These included geographical location of family residence, family size, parental status and socio-economic levels of the families.

The findings indicate that 74.7 per cent of the total research group experienced spina bifida with or without hydrocephalus, while a total of 81.0 per cent of the group experienced hydrocephalus. In the case of those subjects old enough to determine their mobility, some 57.4 per cent were independent in walking, including with the use of a walking-aid, and 33.9 per cent were either dependent in mobility or were bedfast. Approximately 16 per cent of the subjects had been placed in long-term residential care.

Recent developments in treatment are reflected in the number of young children in the group: some 30.8 per cent were aged under 5 years and 15.8 per cent were aged 3 years or less and living at home. Of those subjects aged 4 years and over, not placed in long-term residence but of school age, 57.6 per cent were in regular school placements and 42.4 per cent were in special schools. Of those in special schools (49), 83.7 per cent were in residential school situations (excluding special pre-school).

The families of the total research group were identified in all areas of Queensland, but not distributed between geographic locations in a similar way to the population generally. Some 62.5 per cent of the subjects lived with their families on a full-time basis, while a further 17.1 per cent returned home from residential schools on frequencies ranging over weekly (5.0%), or a terminal basis (6.7%) and annually (5.4%).

The socio-economic status distribution of the families, based on the occupation of the supporting parent or guardian, differed from the Queensland population pattern, with upper category occupations occurring in higher numbers in this group than in the population generally.

Chapter 5 explores family data in more detail for a group of 130 families of infants and school-age subjects, looks at family–social factors related to spina bifida and hydrocephalus, and reviews parental reactions to the birth of their children and assessment of the medical services received by the children and families.

CHAPTER 5

FAMILIES OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS

The research population of 240 children and young adults in this study was characterised by a wide range of ages and levels of functioning. For this reason, it was necessary to undertake a number of studies, each involving specific groups of subjects, in order to explore areas of interest relevant to each group.

This chapter deals with that part of the research which looked at the family–social factors related to spina bifida and hydrocephalus. It is concerned with 130 children and adolescents, aged 0–20 years, and their families. Most were attending formal educational programs at the pre-school, primary and secondary school levels. The data obtained ranged over information on the 130 children and adolescents as a subgroup of the total research population; information to describe their parents and families, including place of residence, and occupations and ages of the parents; and information on the birth of the children, surgical intervention undertaken, details of hospitalisation, and the parents' experiences in relation to the hospitalisation of their disabled children.

Interviews were conducted with one or both parents of the 130 children and adolescents, using a structured interview schedule (Andrews et al. 1978). Due to limitations on the availability of most fathers, only the mothers of the children were usually present, but in 24 cases both parents were present at the interview. The families interviewed were not selected on any particular criterion, except that no attempt was made to contact the parents of the children and young adults in long-term residential care or of those young people who had completed their schooling. Otherwise the parents were of infants and school-age children with whom it was possible to arrange interviews during the course of the research, and regardless of their place of residence.

5.1 THE CHILDREN

Before proceeding to review factors associated with the birth of this group of 130 subjects, and their early medical management, it is useful first to describe them in terms of their age, sex, diagnosis, position in family, and size of family — information against which later data can be evaluated. These and other details for the total group of 240 subjects were presented in Chapter 4.

The 130 subjects whose parents were interviewed were distributed over an age range from birth to 21 years; or across the educational stages of before school, pre-school, primary and secondary school. Forty-seven per cent of this group were male and 53 per cent were female (see also Table 5.1).

A comparison of these data with those given in Chapter 4 shows that the group of 130 subjects is generally representative of the total study group, with the exception that it did not include any subjects who were in long-term residential care or those who had completed their schooling.

The majority (88%) of the children and adolescents were experiencing spina bifida, with some 61 per cent experiencing both spina bifida and hydrocephalus. The

Table 5.1: **Age, sex and diagnosis of children whose parents were interviewed(*a*)**

	Spina bifida only						*Spina bifida/hydrocephalus without shunt*						*Spina bifida/hydrocephalus with shunt*						*Hydrocephalus with shunt*						*All children*					
	B		*G*		*T*		*B*		*G*		*T*		*B*		*G*		*T*		*B*		*G*		*T*		*B*		*G*		*T*	
Age groups(*b*)	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Under 3 years	0	0.0	6	4.6	6	4.6	0	0.0	1	0.8	1	0.8	7	5.4	13	10.0	20	15.4	0	0.0	2	1.5	2	1.5	7	5.4	22	16.9	29	22.3
3 yrs to 5 yrs 11 mos	2	1.5	2	1.5	4	3.1	1	0.8	0	0.0	1	0.8	14	10.8	7	5.4	21	16.2	2	1.5	3	2.3	5	3.8	19	14.6	12	9.2	31	23.8
6 yrs to 11 yrs 11 mos	10	9.7	6	4.6	16	12.3	2	1.5	1	0.8	3	2.3	11	8.4	17	13.1	28	21.5	4	3.1	1	0.8	5	3.9	27	20.7	25	19.3	52	40.0
12 yrs to 20 yrs	3	2.3	4	3.1	7	5.4	2	1.5	0	0.0	2	1.5	2	1.5	4	3.1	6	4.6	1	0.8	2	1.5	3	2.3	8	6.1	10	9.7	18	13.8
Totals	15	11.5	18	13.8	33	25.3	5	3.8	2	1.6	7	5.4	34	26.1	41	31.6	75	57.7	7	5.4	8	6.1	15	11.5	61	46.9	69	53.1	130	100.0

(*a*) Percentages given are for the group of 130 subjects.
(*b*) B = boys, G = girls, T = all children.

This distribution of fathers' occupations can be compared with the male population in Queensland generally. Recent figures from the 1976 census (Australian Bureau of Statistics) indicate the State-wide distribution of males by occupational category to be concentrated at the craftsmen/foremen level, with smaller percentages of employed males in categories V and VI than in the figures for fathers of the research subjects, as presented (see Table 4.9).

There are implications in these data for the socio-economic level of families with a spina bifida and/or hydrocephalic child. As with data presented in Chapter 4, these centre on the higher than average socio-economic status of these families, and especially the concentration of occupations at the managerial and professional levels.

A number of previous research studies (see Chapter 2) have considered problems (if any) of finance and housing in families with a disabled child. The acceptance that difficulty in these areas can exist is reflected in the financial benefits provided to these families within the social welfare programs of many countries, including Australia.

The 130 families interviewed were requested to provide information in this area. Only 5 families (3.8%) reported that they did not have to meet additional financial expense as a result of having a child with spina bifida and/or hydrocephalus. One-third (34.6%) of the families reported that major extra expenditure was incurred, with a slightly smaller percentage of families reporting moderate (31.5%) or little (29.2%) additional expenditure.

The areas reported as being associated with financial hardship are reviewed below. By far the most outstanding aspect was the cost associated with travel to obtain treatment and related services for the handicapped child. Of 114 parents who responded to the request for information on extra costs associated with their handicapped child, 80 (70.2%) listed travel costs as an additional expense and 20 (17.5%) referred to associated accommodation expenses. Three other areas were also dominant in parental responses. Aids, appliances and clothing figured prominently, with extra costs reported to be associated with the purchase of boots and shoes (25.4%), special clothing (11.4%), urinary appliances (10.5%) and the provision of, and repairs to, wheelchairs (7.0%). Transferring the family home, and home alterations to cater for a disabled child, were additional costs experienced by 9.6 per cent and 10 per cent of families respectively. Additional general medical expenses, in respect of the handicapped child, were reported by 11.4 per cent of the 114 families, together with pharmaceutical expenses (7.9%) and the costs of subscriptions to higher benefit scales with health insurance funds (7.0%).

There was evidence that help with the provision of personal aids and appliances, especially from voluntary associations concerned with spina bifida and incontinence, has increased in recent years, but the supply of footwear and wheelchairs remains a difficulty for many families. The parents interviewed generally acknowledged assistance through the Handicapped Children's Allowance with the additional costs of travel, provision of clothing and linen, some pharmaceutical lines and special diets, but the majority considered that they still experienced considerable additional costs in the above areas.

As already indicated, financial hardship can occur as a result of the necessity to change place of residence for reasons associated with a handicapped child; change of residence can also have other major disadvantages, such as separation from family and change in occupation. Of the 130 families studied, 58 (44.6%) had not changed residence since the birth of their child. Of the 71 families who had changed residence, 44 (33.9% of the total group) reported changing residence to meet needs associated with their spina bifida child. The majority of these, 28 families changed residence to

Table 5.8: **Nature of change of residence, and reasons given for change**(*a*)

	Within metropolitan area		*Other urban to metropolitan area*		*Within other urban area*		*Rural to metropolitan*		*Rural to other urban*		*Within rural areas*		*Outside Qld to met./urban areas*		*Other*		*Total*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
For medical reasons	2	1.5	5	3.8	2	1.5	6	4.6	6	4.6	1	0.8	1	0.8	3	2.3	26	20.0
For more suitable housing	8	6.2	1	0.8	5	3.8							1	0.8	1	0.8	16	12.4
For more suitable schooling	1	0.8							1	0.8							2	1.5
Family reasons not directly related to child's requirements	5	3.8	1	0.8	3	2.3					1	0.8	5	3.8	3	2.3	18	13.8
Other reasons	3	2.3			1	0.8			1	0.8	1	0.8	1	0.8	2	1.5	9	6.9
Sub-totals	19	14.6	7	5.4	11	8.5	6	4.6	8	6.2	3	2.3	8	6.2	9	6.9	71	54.6
No change of residence reported and missing data(*b*)																	59	45.4
Totals																	130	100.0

(*a*) Percentages given are for the group of 130 subjects. Percentages are rounded.

(*b*) Of the 59 families who have not changed residence, 31 live in the metropolitan area, 23 in other urban areas, 1 in a rural area, while for 4 families the data were not available.

be nearer medical help and 16 families changed residence to move to housing more suited to the needs of the disabled child. At the same time it is interesting to note that only 2 families changed their place of living to be nearer to more suitable schooling.

Table 5.8 sets out data which analyses change in residence, based on geographical location. The highest frequencies in the table indicate that families tended to move for medical reasons if they moved from other urban areas to the metropolitan area or from rural to urban areas, while families who moved their place of residence to achieve more suitable housing moved within the metropolitan or other urban areas. The majority of cases moving from outside of Queensland to urban areas within this State did so due to change in fathers' employment.

5.3 PARENTS' EXPERIENCES AT CHILD'S BIRTH AND SOON AFTER

The birth of a child with spina bifida and/or hydrocephalus can be a difficult experience for the parents, as with the birth of children with other handicaps. However, with reference to spina bifida, few conditions require virtually immediate decisions to be taken about the child's future, often necessitating surgical intervention within a matter of days following birth. Details of the parents' reactions to the birth of their children and subsequent hospitalisation, as well as advice and decisions about the children's difficulties, and the parents' experiences when faced with these circumstances, are reported in this section.

In recent years much has been written about the effects of the birth of a handicapped child on parents and families. The consensus to be extracted from these studies is that parental reactions differ significantly, and that parents have very individual needs in the days and weeks following the birth of their child.

In this study, some specific aspects of parental relationships following the birth of the child, and parent–child relationships, were explored rather than generalised emotional reactions. The data setting out the parents' reports of the effect of the birth of their disabled child on their marital relationships are in Table 5.9. Parents of about one-half of the families (44.6%) reported a cohesive effect from this experience, while 17.7 per cent reported that the child's birth had a disruptive effect on their relationships. A substantial number of parents (21.6%) reported no effect on their relationships, while 16 families did not give a response. These findings tend to represent a higher percentage of families reporting a positive effect on the parental marital relationship, and a lower percentage reporting a negative effect, than in the studies reviewed in Chapter 2, although they are broadly similar to the findings

Table 5.9: **Effect of disabled child on marital relationships**

Type of effect	*No. of families*	*Per cent of group*	
Strong cohesive effect on relationships	14	10.8	44.6
Cohesive effect	44	33.8	
Disruptive effect on relationships	18	13.8	17.7
Strong disruptive effect	5	3.9	
No difference in relationships	28	21.6	
No response	16	12.3	
Not applicable	2	1.5	
Missing information	3	2.3	
Totals	130	100.0	

reported in the literature review. Some qualifications of the data, however, needs to be given. The responses were given by parents with differing periods of elapsed time since the birth of their handicapped child. Some children were recent births, others were in their adolescent years. It was noted that some of the parents tended to be conscious of what the interviewer would expect of the mother of a handicapped child, and on occasions, when marital disruption was reported, it was stated to be caused by other members of the family, usually a sibling. In addition, few fathers were interviewed (a total of 26) and the mothers may not always have been aware of the fathers' perceptions of their marital relationships.

The mothers in the group also reported on the extent of help that was offered by their spouse in the management of the disabled child. With 5 of the 130 families interviewed being 1-parent homes (mother only), 99 mothers (76.2%) reported their spouse helped with management, while 26 (20.0%) reported their husband was unable to assist them. In further questioning of the mothers, it was found that, beyond the usual assistance provided by fathers with household activities such as transporting children and helping with household management and family chores, 76 of 112 mothers reported that their husbands would assist in all aspects of management of the spina bifida child. This included help with urinary appliances and other tasks specific to the child's needs.

In discussing parents' reactions to the birth of their handicapped child, it can also be noted that most mothers seemed ready to have another child after the birth of a spina bifida or hydrocephalic baby. Only 2 mothers reported that their child presented difficulties or consumed so much time that it would not be practicable to attempt to care for more children, and these mothers did not give the impression that they sought to have their child cared for by someone else.

Some 34 per cent of families with at least 2 children reported they treated their disabled child differently, while the remaining two-thirds of the families reported no difference in treating this child compared with their other children. The reported differences, however, reflected the need in most families to treat children differently, according to the personalities of the family members and their rapport with each other, and that the handicapped child was treated no differently in respect to training and discipline.

Of the 130 children whose parents were interviewed, 69.3 per cent (90) were delivered in public hospitals in Queensland, nearly half of these in hospitals in metropolitan Brisbane. Slightly more than 22 per cent (29) were delivered in the State's private hospitals, while 8.4 per cent (11) were born outside of Queensland (see Table 5.10).

Subsequent to birth, 58.5 per cent (76) of the children were treated mainly at the Royal Children's Hospital (Table 5.11), with a further 20.8 per cent (27) treated in the Mater Children's Hospital, both located in inner Brisbane. Only 5.3 per cent (7) of the children received most of their treatment in provincial hospitals, although 40.7 per cent (53) of the children were born in provincial and rural hospitals. Significantly, 12.3 per cent of all cases (16) were largely treated privately by specialists. It is emphasised, however, that nearly 80 per cent (103) of the children received their primary medical treatment at the 2 Brisbane children's hospitals.

It should be noted that 16 children (12.3%) experienced hydrocephalus only, and the urgency to transfer these children for surgical intervention would not be as great, even if their hydrocephalus were diagnosed in the first few days of life.

Nearly 50 per cent of the mothers were advised they had given birth to a disabled child by the delivering obstetrician. This source was followed in 20.8 per cent of cases by general practitioners, with the husband being the next highest frequency reported (9.2%). All together, some 78 per cent of mothers were advised by a general practitioner or medical specialist and 5.4 per cent by nursing staff. In very few cases was the information about the child's condition not given to the parent.

Nearly half the mothers were advised of the child's condition immediately following delivery, and 80.7 per cent had been advised within 12 hours of the birth. In 16 cases (12.3%), the mother was not advised until periods ranging from 3 weeks to 69 weeks following delivery. In 2 of these cases, hydrocephalus had not developed until the 5th and 9th weeks after birth respectively, while the others appear to be late diagnoses, rather than withholding of information.

Table 5.10: **Location of hospitals where children were delivered**

Location of hospitals	*No. of children*		*Per cent of group*	
Metropolitan				
Metropolitan Public	50	66	38.5	50.9
Metropolitan Private	8		6.2	
Greater Brisbane Public	8		6.2	
Other urban				
Provincial Public	21	37	16.1	28.4
Provincial Private	16		12.3	
Rural				
Country Public	11	16	8.5	12.3
Country Private	5		3.8	
Other locations				
Interstate	6		4.6	
Overseas	5		3.8	
Totals	130		100.0	

Table 5.11: **Place where children received most treatment**

Place of treatment	*No. of children*	*Per cent of group*	
Metropolitan Public Hospitals			
Royal Children's Hospital	76	58.5	79.3
Mater Children's Hospital	27	20.8	
Metropolitan Private Hospitals	4	3.1	
Provincial Public Hospitals	5	3.8	
Provincial Private Hospitals	2	1.5	
By specialists privately	16	12.3	
Totals	130	100.0	

In 45 per cent of cases the mother was advised about her child's condition without anyone else being present. The husband was present in 30.8 per cent of instances, and a nurse in 11.5 per cent of cases. Other persons present account for the remainder (7.7%) of subjects, this information being unknown for 4.6 per cent of cases.

Parents were asked to report how they reacted to the information about their child's condition. Responses varied, but by far the most common was a range of descriptions used to describe an emotional reaction. The word 'shock' was used 42 times to describe his experience; 'disbelief' was used 22 times; 'upset', 18 times; 'numbness', 12 times; and 'confusion', 'unreality' and 'depressed' were used 8, 4 and 3 times respectively. Five parents mentioned feeling guilty. Four were not aware of the implications or were untroubled because they did not know there was a problem. Two parents were relieved that the child had survived, assured by a knowledge that there was no mental retardation. Thirteen mothers and 1 father reported premonitions that all was not well with the child, and 3 of these were not at all surprised when told that the child was handicapped.

The responses of 15 mothers reflected their concern for the child directly in that they were worried about the child's welfare and future, while 1 mother worried about her ability to cope with the child. Fifteen also reported their acceptance of the situation from first knowledge of the child's problem. Only 1 mother actually used the word 'disappointment' when referring to the experience.

In approximately half the cases (50.8%), the mothers reported that the parents had an opportunity to discuss what was involved in the disorder. But, equally significant, the opportunity for discussion was not available in some 47 per cent of cases. Sixty-one parents did not have any opportunity to discuss what was involved.

Information on who was available for discussion was obtained in 95 cases. For 63 of the 95 mothers, or 66.3 per cent of the applicable cases, the mother was able to discuss the disorder with a medical practitioner. Additional persons with whom discussion was possible included social workers (6.3%, 6 cases), and other parents of a spina bifida child (2.1%, 2 cases). These figures are slightly different from those given in the preceding paragraph, where only 50.8 per cent (66) of all mothers reported they had opportunity to discuss what was involved in the disorder, but this is due to the difference between a perceived opportunity for immediate discussion, and discussion within a reasonable period of time.

A substantial number of parents perceived problems with information to be the result of (a) no one being available with any knowledge of the condition (24 mothers, half of whom were confined outside the metropolitan area); (b) refusal to discuss, or delay by medical personnel in discussion of the problem (17 parents; in the case of 9, information was made available gradually); while (c) 5 parents reported the shock of the birth resulted in their inability to recall the event.

Some earlier studies emphasised the importance of providing parents with adequate opportunity to understand and assimilate information following the birth of a disabled child. In this study, only 35.4 per cent of mothers (46) indicated that they fully understood the information given to them following the delivery of their child. Some understanding was reported by 31.5 per cent (41), but 28.5 per cent (37) of the parents reported that they understood only a little of the information given to them.

These figures are reflected in the data on parent satisfaction with the information they were given. While 60 per cent of the group reported they were satisfied, 36.2 per cent were not satisfied with the information given. Five parents (3.8%) gave no response to this item. Parents responses in this area overwhelmingly urge the need for earlier and fuller explanations of the condition of the child couched in non-medical terms. Following that, parents sought continued discussion about their child, especially during the initial hospitalisation.

The 130 parents were asked to indicate any change in their feelings about the child's disability since the initial information was received, soon after delivery. By far the majority of parents (approximately 78%) reported a change in their feelings. Parents who reported a change in their feelings indicated, as might be expected, that this was mainly in the area of increased acceptance of the child. Twenty-eight parents stressed on this occasion the 'normality' of their child. A further 69 remarked on their acceptance and understanding of the problem, and of their special love for the child, while 8 parents stated that they had changed in their approach to the problems experienced, could now cope, and were more positive persons. On the other hand, 3 of the parents reporting that their feelings had not changed were far from optimistic, and 1 said she had changed by being less stable now than she had been previously.

The parents interviewed also indicated (Table 5.12) that they now discussed their concerns and feelings mostly with their spouse (40.8% of the group), a professional person (15.4%), relatives (11.5%) and friends (8.5%). In contrast, only 5.4 per cent of the group reported they used the services of the Spina Bifida Association of Queensland for this purpose and 3.1 per cent discussed their concerns with a member of the clergy. However, 13.8 per cent (18 parents) indicated that they had no one with whom they could discuss their concerns and feelings. It should also be noted that 6 mothers indicated receiving help also from discussions with the mother of another spina bifida child.

Table 5.12: **Information on persons with whom parents now discuss concerns and feelings**

Persons	*No. of parents*	*Per cent of group*
Spouse	53	40.8
Professional person	20	15.4
Relatives	15	11.5
Friends	11	8.4
S.B. Association officer	7	5.4
Clergy	4	3.1
No one available	18	13.8
Not applicable, missing data	2	1.6
Totals	130	100.0

In the wider aspect of help received in the management of their child, 82.3 per cent of families (107) reported receiving assistance from relatives, friends and neighbours, although 16.2 per cent (21) received no help with their child in this way. It can be noted by comparison that in data reported in the preceding paragraph, only 20 per cent of families reported they were able to discuss their concerns and feelings with relatives and friends, and 13.8 per cent reported that they had no one with whom to discuss their concerns.

Of the sources of help available, the families of the parents provide most assistance — in 63.6 per cent of cases — while friends and neighbours provide help in 23.4 per cent of cases. Paid help was available to only 7 per cent of families.

5.4 LATER HOSPITAL EXPERIENCES

Selection of a spina bifida child for surgery is an important aspect of the total post-birth treatment process and the parents' understanding and acceptance of their child. Table 5.13 gives details of the degree of consultation parents had with medical

Table 5.13: **Extent to which consultation with medical practitioners occurred with regard to initial surgery: by location**

	No consultation		*Some consultation*		*Consultation to a great extent*		*No response*		*Total*	
Location	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Metropolitan hospitals	25	44.6	18	32.1	11	19.6	2	3.6	56	100.0
Other urban hospitals	16	37.2	17	39.5	9	10.9	1	2.3	43	100.0
Rural hospitals	14	66.6	4	19.0	2	9.5	1	4.8	21	100.0
All hospitals	55	45.8	39	32.5	22	18.3	4	3.3	120	100.0

Table 5.14: **Extent to which parents were involved in daily care of the child during first admission: by location** (*a*)

	Not involved		*Moderately involved*		*Fully involved*		*No response*		*Totals*	
Location	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Metropolitan hospitals	22	39.3	20	35.7	10	17.9	4	7.1	56	100.0
Other urban hospitals	14	32.6	15	34.9	11	25.5	3	7.0	43	100.0
Rural hospitals	3	14.3	10	47.6	4	19.1	4	19.1	21	100.0
All hospitals	39	32.5	45	37.5	25	20.8	11	9.2	120	100.0

(*a*) Data is not reported for 10 cases, 9 of whom were born outside Queensland. Percentages given are for each category of hospital.

practitioners about initial surgery. The data in the table do not include information for 9 children born outside of Queensland, and there was 1 case of missing data. It will be seen that 45.8 per cent of the 120 parents report that no consultation took place. Consultation to some extent occurred in 32.5 per cent of cases, and only in 18.3 per cent of cases did parents report considerable discussion on the need for, and plans for, surgery. The major area of difference in opportunity for consultation is in the figures for rural hospitals, but it is likely that transfer of the child to a metropolitan hospital accounts for the increased lack of consultation reported.

Surgery to repair the lesion usually requires the transfer of the child to special services, and the mother's opportunity to nurse or hold the child before their separation may be restricted. Of the 130 mothers, 72 (55.4%) reported that they were not able to hold the child before transfer, 32 (24.6%) were allowed only briefly to hold their child and 19 (14.6%) reported that they were permitted a sufficient amount of nursing. This information was not available in 7 cases.

Mothers were also asked to what extent encouragement had been received from hospital staff to nurse their child during the first admission, that is, at the hospital to which the child was transferred for treatment or surgery. Forty-seven mothers (36.2%) reported they received no encouragement, while 74 (56.8%) were encouraged to nurse their child. This information was not available for 9 subjects.

Apart from encouragement and opportunity to hold and nurse their child before initial surgery, parents' general level of satisfaction with their own involvement in the initial treatment stage was explored. Adequate involvement was reported by 61.5 per cent of the parents, but inadequate involvement by 31.6 per cent. Missing data accounted for 4.6 per cent of the responses and 2.3 per cent of parents (3) did not provide the information.

Of those parents who reported adequate involvement, the activities described were in almost all instances centred on nursing, feeding and bathing of the child.

5.4.1 Daily care of child during first admission

Table 5.14 gives details of the extent to which parents were involved in daily care of their children during the first admission, that is, the hospitalisation for initial surgery and/or treatment immediately after birth. It will be noted that nearly one-third (32.5%) of mothers were not involved at all in daily care, while one-fifth (20.8%) reported they were fully involved. A group representing more than one-third of the mothers reporting (37.5%) were moderately involved.

Of those who were not involved in daily care, the largest proportion occurred in metropolitan hospitals, followed by the other urban group of hospitals. However, the other urban hospitals produced the largest proportion of parents who reported they were fully involved in daily care of their child.

5.4.2 Length of the first hospitalisation

The length of first hospitalisation varied significantly for the 130 children studied (Table 5.15). More than one-half (52.9%) were hospitalised from birth for a period exceeding 4 weeks. The next most frequent length of stay in hospital was from 1 to 2 weeks. This pattern tends to hold true over the 4 age groups employed in the analysis reported in the table, reflecting little if any change in length of first hospitalisation over the last 2 decades.

In respect to the frequency of visits paid by parents to their child during the first hospitalisation, the majority of parents (62.3%) for whom this information was available visited their child daily. Approximately 87 per cent of parents visited their child at least once a week. Of the 5 cases where parents did not visit the child they were prevented by their own health or family needs.

Table 5.15: **Length of time of first stay in hospital: by age(*a*)**

	Age groups													
	Under 3 yrs			*3 yrs to 5 yrs 11 mths*			*6 yrs to 11 yrs 11 mths*			*12 yrs to 20 yrs*			*All age groups*	
Length of stay	*No.*	%		*No.*	%		*No.*	%		*No.*	%		*No.*	%
Less than 1 week	1	0.8	(3.4)	3	2.3	(9.7)	1	0.8	(1.9)				5	3.9
1 to 2 weeks	4	3.1	(13.8)	5	3.8	(16.1)	11	8.5	(21.1)	4	3.1	(22.2)	24	18.5
2 to 3 weeks	4	3.1	(13.8)	4	3.1	(12.9)	8	6.1	(15.4)	1	0.8	(5.6)	17	13.1
3 to 4 weeks	4	3.1	(13.8)	4	3.1	(12.9)	3	2.3	(5.8)	1	0.8	(5.6)	12	9.3
More than 4 weeks	16	12.3	(55.2)	14	10.7	(45.2)	29	22.3	(55.8)	10	7.5	(55.5)	69	52.8
				1	0.8	(3.2)				2	1.6	(11.1)	3	2.4
Totals	29	22.4	(100.0)	31	23.8	(100.0)	52	40.0	(100.0)	18	13.8	(100.0)	130	100.0

(*a*) Percentages given are for total group, except those in parentheses, which apply to each age group.

5.4.3 Subsequent admissions

Children with spina bifida face many admissions to hospital for surgical and/or medical purposes. Of the 126 children for whom data was available on the frequency of admissions to hospital up to the time of the present interview, more than one-quarter (26.2%) had been admitted on more than 12 occasions. Table 5.16 shows the information for other frequency levels, with some 82 per cent of the children having been admitted to hospital more than 3 times. The modal point is in the range from 7 to 9 hospital admissions. These figures are, of course, influenced by the age distribution of the children.

Table 5.16: **Frequency of hospital admissions**

Frequency of admissions	*No. of children*	*Per cent of valid cases*
Less than 3 admissions	23	18.3
3 to 6 admissions	34	27.0
7 to 9 admissions	24	19.0
10 to 12 admissions	12	9.5
More than 12 admissions	33	26.2
Missing data	4	–
Totals	130	100.0

Table 5.17 sets out details of the estimated length of time spent in hospital for each admission after the first compared on an age basis. It will be noted that time totalling 5–10 days is the most common average length of stay, although average time spent in hospital of 10–15 days is most frequent in subjects aged 12–20 years. These figures, of course, are also influenced by the age distribution of the children within the 130 families interviewed, regardless of presentation on a basis of age.

5.4.4 Frequency of surgery

Table 5.18 sets out the frequency of surgery undergone by the 130 children, analysed on the basis of age and sex. While the data are undoubtedly influenced by the age of the children and adolescents studied, firm patterns emerge. For the 3 age groups covering the period from 3 years to 20 years the highest entries in respect to frequency of surgery are in the 'more than eight' category, with 29.1, 25.0 and 38.9 per cent of subjects in each of the 3 age groups respectively. There is also a marked 'bulge' in the amount of surgery at the 'two', 'three' and 'four' frequency levels. For the age group under 3 years, the largest numbers occur in the 'one' to 'four' frequency levels, as might be expected. Modal points for the 4 age levels employed in the table are within the 2-, 4-, 5- and 7- to-8-year age levels in ascending order, indicating that the number of surgical operations undergone by the subjects for spina bifida, hydrocephalus and associated disorders is fairly age dependent.

In respect to the analysis based on the sex of the subjects, no strong trends are evident. Females have slightly higher averages for frequency of surgery at the 2 upper age levels, with males slightly higher in averages at the 2 lower age levels.

5.4.5 Parental satisfaction with various hospital services

The foregoing sections, which presented the findings on frequency of hospitalisation and surgery and parental visits to the child while in hospital, clearly indicate the

Table 5.17: **Average length of time spent in hospital on each subsequent admission: by age of child**(*a*)

	Age groups													
	Under 3 years			*3 yrs to 5 yrs 11 mos*			*6 yrs to 11 yrs 11 mos*			*12 yrs to 20 yrs*			*All age groups*	
Length of stay	*No.*	*%*		*No.*	*%*		*No.*	*%*		*No.*	*%*		*No.*	*%*
1 to 5 days	8	6.2	(27.6)	5	3.8	(16.1)	6	4.6	(11.5)				19	14.6
5 to 10 days	12	9.2	(41.4)	14	10.8	(45.2)	22	16.9	(42.3)	5	3.8	(27.8)	53	40.7
10 to 15 days	5	3.8	(17.2)	9	6.9	(29.0)	11	8.5	(21.2)	11	8.5	(61.1)	36	27.7
Over 15 days	1	0.8	(3.4)	2	1.5	(6.5)	10	7.7	(19.2)	1	0.8	(5.55)	14	10.8
Not applicable or no response	3	2.3	(10.4)	1	0.8	(3.2)	3	2.3	(5.8)	1	0.8	(5.55)	8	6.2
Totals	29	22.3	(100.0)	31	23.8	(100.0)	52	40.0	(100.0)	18	13.9	(100.0)	130	100.0

(*a*) Percentages given are for total group, except those in parentheses, which apply to each age group.

Table 5.18: **Frequency of surgery: by age and sex of subjects**(*a*)

	Under 3 years						*3 yrs to 5 yrs 11 ms*						*6 yrs to 11 yrs 11 ms*						*12 yrs to 20 yrs*						*All age groups*					
Number of surgical operations	*B*		*G*		*T*		*B*		*G*		*T*		*B*		*G*		*T*		*B*		*G*		*T*		*B*		*G*		*T*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Nil			1	3.4	1	3.4													1	5.6 (0.8)			1	5.6 (0.8)	1	(0.8)	1	(0.8)	2	(1.5)
One			5	17.2 (3.8)	5	17.2 (3.8)			1	3.2 (0.8)	1	3.2 (0.8)	1	1.9 (0.8)	3	5.8 (2.3)	4	7.7 (3.1)							1	(0.8)	9	(6.9)	10	(7.7)

Two	3 10.3 (2.3)	6 20.7 (4.6)	9 31.0 (6.9)	3 9.7 (2.3)	3 9.7 (2.3)	6 19.4 (4.6)	1 1.9 (0.8)	3 5.8 (2.3)	4 7.7 (3.1)	1 5.6 (0.8)		1 5.6 (0.8)	8 (6.2)	12 (9.3)	20 (15.5)
Three	2 6.9 (1.6)	4 13.8 (3.1)	6 20.7 (4.7)	3 9.7 (2.3)	1 3.2 (0.8)	4 12.9 (3.1)	4 7.7 (3.1)	1 1.9 (0.8)	5 9.6 (3.9)				9 (6.9)	6 (4.6)	15 (11.5)
Four	1 3.4 (0.8)	4 13.8 (3.1)	5 17.2 (3.8)	3 9.7 (2.3)	2 6.4 (1.6)	5 16.1 (3.9)	6 11.5 (4.6)	3 5.8 (2.3)	9 17.3 (6.9)	1 5.6 (0.8)	2 11.1 (1.5)	3 16.7 (2.3)	11 (8.5)	11 (8.5)	22 (17.0)
Five							5 9.6 (3.8)	1 1.9 (0.8)	6 11.5 (4.6)		1 5.6 (0.8)	1 5.6 (0.8)	5 (3.8)	2 (1.5)	7 (5.4)
Six		1 3.4 (0.8)	1 3.4 (0.8)	3 9.7 (2.3)	1 3.2 (0.8)	4 12.9 (3.1)	1 1.9 (0.8)	3 5.8 (2.3)	4 7.7 (3.1)		2 11.1 (1.6)	2 11.1 (1.6)	4 (3.1)	7 (5.4)	11 (8.5)
Seven	1 3.4 (0.8)		1 3.4 (0.8)	1 3.2 (0.8)	1 3.2 (0.8)	2 6.4 (1.6)	2 3.8 (1.5)	2 3.8 (1.5)	4 7.7 (3.0)		1 5.6 (0.8)	1 5.6 (0.8)	4 (3.1)	4 (3.1)	8 (6.2)
Eight							1 1.9 (0.8)	2 3.8 (1.5)	3 5.8 (2.3)	2 11.1 (1.5)		2 11.1 (1.5)	3 (2.3)	2 (1.5)	5 (3.8)
More than eight		1 3.4 (0.8)	1 3.4 (0.8)	6 19.4 (4.6)	3 9.7 (2.3)	9 29.1 (6.9)	6 11.5 (4.6)	7 13.5 (5.4)	13 25.0 (10.0)	3 16.7 (2.3)	4 22.2 (3.1)	7 38.9 (5.4)	15 (11.5)	15 (11.5)	30 (23.0)
Totals	7 24.1 (5.4)	22 75.9 (16.9)	29 100.0 (22.3)	19 61.3 (14.6)	12 38.7 (9.3)	31 100.0 (23.9)	27 51.9 (20.8)	25 48.1 (19.2)	52 100.0 (40.0)	8 44.4 (6.1)	10 55.6 (7.7)	18 100.0 (13.8)	61 (47.0)	69 (53.0)	130 (100.0)

(a) Percentages given are for age groups, except those in parentheses, which apply to the total group.

extent of medical and surgical involvement experienced by the children. In addition to hospitalisation, however, these children and their parents are engaged in frequent visits to hospital out-patient clinics for routine assistance, or visits to private specialists. This section is concerned with assessing the reactions of parents to the help and assistance received in hospitals and to various hospital services. Many of the analyses presented take account of regional differences in parental assessment of these services, as well as differences between reports by parents from different socio-economic levels.

In considering the degree of satisfaction expressed by parents in regard to medical services generally, it can be noted that by far the majority of parents were satisfied or very satisfied with help in this area (a total of nearly 84%), with some 12 per cent reporting that they were not satisfied.

Apart from overall medical services, Table 5.19 indicates similar data for a range of other hospital services. The high frequency of contact many parents of spina bifida children have with hospital services, and the potential stress and difficulties associated with the medical aspects of the condition, suggest the desirability of making these services as accessible as possible and generally supportive of the parents. The data in Table 5.19 show clearly those specific hospital services with which parents reported a lack of satisfaction — namely, making out-patient appointments, the waiting-time involved in out-patient clinics, clinics which did not have co-ordinated services which reduced the search for treatment, and car-parking provisions at hospitals. However, the table shows much higher levels of satisfaction with medically related services, such as provision of appliances and access to specialists.

Table 5.19: **Degree of satisfaction with various, specific hospital services**

Type of service	*No. of respondents*	*Per cent of total group*	*Satisfied*		*Not satisfied*	
			No.	*%*	*No.*	*%*
Making out-patient appointments	82	63.1	39	47.6	43	52.4
Waiting in out-patient clinics	81	62.3	19	23.5	62	76.5
Unco-ordinated S.B./H. clinics	61	46.9	16	26.2	45	73.8
Provisions for emergency admissions	56	43.1	35	62.5	21	37.5
Provisions for car parking	89	68.5	6	6.7	83	93.3
Provision of orthopaedic appliances	62	47.7	46	74.2	16	25.8
Provision of urinary appliances	56	43.1	45	80.4	11	19.6
Access to specialists	96	73.8	69	71.9	27	28.1

The data in Table 5.19 are further amplified in the following pages. It will be noted in this section that the number of parents responding to the request for information differed from 1 type of service to the next. For summary purposes, the percentage of parents responding in regard to each type of service is presented within Table 5.19, although the information also is reported later. This difference in the number of parents responding to these items is due to some extent to their differing needs for, and use of, the services provided by hospitals.

Making out-patient appointments

Eighty-two parents (63.1% of the parents interviewed) responded to this item. The remaining 48 parents interviewed expressed no views, mainly because they had not had any experience of out-patient clinics either because it had not been necessary to use them or because they consulted private practitioners. Of these 48 parents, 18 were classified as being in the socio-economic categories based on professional and managerial positions (Group I); 21, based on clerical, craftsmen and foremen positions (Group II); and 5 in Group III (shop assistants; personal, domestic and service workers; pensioners and unemployed)[1]. Occupation was unknown in four cases.

In respect to the 82 respondents to the item on satisfaction with procedures for making out-patient appointments, Table 5.20 indicates their responses, based on place of resident. It will be noted that the responses for each residential location are divided approximately on a one-third/two-thirds basis; but that 69 per cent of the metropolitan respondents were dissatisfied with the procedures, while 65 per cent and 62 per cent respectively of the other urban and rural respondents were satisfied with procedures for making out-patient appointments. Overall, the responses tended slightly towards dissatisfaction.

Table 5.20: **Analysis of responses on procedures for making out-patient appointments: by location of residence**

Location of residence	*Satisfied*		*Dissatisfied*		*Total responding*		*No response given*
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*
Metropolitan	13	13.0	29	69.0	42	100.0	25
Other urban	21	65.6	11	34.4	32	100.0	18
Rural	5	62.5	3	37.5	8	100.0	5
All locations	39	47.6	43	52.4	82	100.0	48

Table 5.21 gives a further breakdown of these results by location of residence and socio-economic status. The table indicates that dissatisfaction with these procedures, while most marked in the metropolitan area, tends also to be associated with higher socio-economic families.

Waiting-time in out-patient clinics in public hospitals

There were 81 respondents (62.3% of the group) to this item. Of the 49 parents who did not respond, 18 were in socio-economic Group I, 5 were in each of Group II and Group III, with 5 of unknown occupation. It was noted that many of the parents who failed to respond did not use public hospital out-patient facilities.

Table 5.22 gives details of the responses for the 81 parents, based on location of residence. It will be seen that dissatisfaction with waiting-time is very high in the metropolitan area, less so in other urban areas, and that opinions are towards satisfaction in rural areas.

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[1] These occupational groups to estimate socio-economic categories of families are based on the data presented in Chapter 4. The descriptions here should be used to interpret similar data in the following pages.

Table 5.21: **Parental satisfaction with procedures for making out-patient appointments: by location of residence and socio-economic category(*a*)**

	Socio-economic categories (a)											
	I (n = 22; 26.8%)				*II (n = 43; 52.8%)*				*III (n = 17; 20.7%)*			
	Satisfied		*Dissatisfied*		*Satisfied*		*Dissatisfied*		*Satisfied*		*Dissatisfied*	
Location of residence	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Metropolitan	1	4.5	11	50.0	8	18.6	13	30.2	4	23.5	5	29.4
Other urban	4	18.2	2	9.1	12	27.9	7	16.3	5	29.4	2	11.8
Rural	4	18.2					3	7.0	1	5.9		
All locations	9	40.9	13	59.1	20	46.5	23	53.5	10	58.8	7	41.2

(*a*) See Chapter 4 for description of socio-economic categories. Percentages given are for each socio-economic group.

Table 5.22: **Analysis of responses on waiting-time in out-patient departments: by location of residence**

Location of residence	*Satisfied* *No.*	*Satisfied* *%*	*Dissatisfied* *No.*	*Dissatisfied* *%*	*Total responding* *No.*	*Total responding* *%*	*No response given* *No.*
Metropolitan	3	7.2	39	92.8	42	100.0	25
Other urban	12	38.7	19	61.3	31	100.0	19
Rural	4	50.0	4	40.0	8	100.0	5
All locations	19	23.5	62	76.5	81	100.0	49

These figures are further broken down in Table 5.23, in respect of place of residence and socio-economic level of family. The results show a strong dissatisfaction with waiting-time in out-patient clinics over all socio-economic levels, and especially in the metropolitan area, with a further notable response for families in other urban areas of socio-economic Category II.

Parental views on unco-ordinated clinics

Co-ordinated clinics, which provide services to families with a severely handicapped child, are hospital clinics which have, at the one location, all the medical and support services needed by families for the health care of their child. These services include relevant therapy, assistance with appliances, and access to an orthopaedic surgeon, neuro-surgeon, urologist and stomal therapist.

There were 61 respondents (46.9% of the group) to this item. Of those parents not responding, 24 were in socio-economic Group I, 31 were in Group II, 9 were in Group III. Socio-economic group was unknown in 5 cases. Dissatisfaction with unco-ordinated clinics was greatest in the metropolitan area; but a larger proportion of parents living in other urban and rural areas was also dissatisfied with this service. Overall the results indicate the difficulty and stress experienced by parents who need to seek various medical services from a number of clinic locations, even remembering that the data was provided by only 47 per cent of the group interviewed. This dissatisfaction is present in families of all socio-economic groups, but more particularly among parents in Groups I and II.

Provisions for emergency admissions

Only 56 parents (43.1% of those interviewed) responded to this item. High levels of satisfaction with procedures for emergency admissions were expressed by parents in other urban and rural locations of Queensland, but metropolitan parents were fairly evenly divided on the question. This satisfaction was most marked among families in socio-economic Groups I and II (approximately 78% of each group reporting satisfaction with the services).

Provisions for car parking

Because of the high incidence of mobility problems in children with spina bifida (only some 25 per cent of the 240 cases surveyed were independent in walking), hospital attendance is made more difficult. Some 89 parents (68.5% of the 130 parents interviewed) responded to the request for information on their level of satisfaction

Table 5.23: **Parental satisfaction with waiting-time in out-patient clinics: by location of residence and socio-economic category**

	Socio-economic categories (a)											
	I (n = 22; 27.1%)				*II (n = 42; 51.9%)*				*III (n = 17; 21.0%)*			
Location of residence	*Satisfied*		*Dissatisfied*		*Satisfied*		*Dissatisfied*		*Satisfied*		*Dissatisfied*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Metropolitan			12	54.5	2	4.8	19	45.2	1	5.9	8	47.1
Other urban	4	18.2	2	9.1	4	9.6	14	33.3	4	23.5	3	17.6
Rural	2	0.1	2	9.1	2	4.8	1	2.4			1	5.9
All locations	6	27.3	16	72.7	8	19.2	34	80.9	5	29.4	12	70.6

(*a*) See Chapter 4 for description of socio-economic categories. Percentages given are for each socio-economic group.

with parking provisions at hospitals. Parents' level of dissatisfaction with parking provisions was high in all residential locations and for all socio-economic groups. These results are the most marked of all the specific hospital services considered, with an overall 93.3 per cent of parents expressing dissatisfaction. Of the 41 parents not responding to this item, 15 were identified as being in socio-economic Group I; 19, in Group II; and 2, in Group III — which may indicate that poorer families do not have a car for the mother to use in visiting the hospital.

Orthopaedic and urinary appliances

The response level in respect to provision of orthopaedic appliances was low (47.7% of the group), but generally parents in all residential areas expressed satisfaction with this service. The proportion of parents who were satisfied in this area was highest in the lower socio-economic Groups I and II.

This pattern of responses was much the same for that in respect to the provision of urinary appliances. A high proportion of the parents reported satisfaction with the service in all residential areas and over all socio-economic groups.

The large number of parents not providing information on the provision of orthopaedic and urinary appliances was mostly due to cases where an appliance was not required or was obtained privately.

Availability of specialists

Results in this section tend to reflect those in the previous one. By far the majority of parents expressed satisfaction with the availability of specialists in public hospitals, a result consistent over all residential locations and socio-economic groups. However, of the parents reporting dissatisfaction with the availability of specialists, more than half made strong complaints about the lack of communication between themselves and specialists, a number stating that medical students always had precedence for the time apparently available.

5.4.6 Overall satisfaction with hospital services

Parental satisfaction with hospital services is dichotomised on the basis of services being directly medically based or not. In other words, parents in most residential locations, and of most socio-economic levels, expressed greater satisfaction with the provision of emergency services, provision of appliances, and access to medical specialists than they did with making and waiting for out-patients appointments, the availability of various needed treatment services at the one location, and the availability of adequate car-parking arrangements. Dissatisfaction with the latter services was far greater in the metropolitan area than in the provincial cities and rural areas, and also tended to be greater, or more forcibly expressed, among parents of higher socio-economic levels.

While it would seem that hospitals offer parents with severely handicapped children satisfactory medical services, there is good reason for them to consider the need to improve the non-medical aspect of their service to these families. Parents of severely handicapped children face problems of accessibility to services in respect of the time involved in making appointments and waiting for out-patient treatment, movement from one type of service to another, and parking of their cars in positions which can ease the mobility and handling difficulties associated with many physically disabled children.

For instance, there was severe criticism of steps at hospitals which needed to be negotiated to move from service to service. Several parents mentioned the distance between services, for example the splintmaker and the physiotherapy clinic, and often difficult access from casualty areas to wards for treatment.

There was also criticism of toilet facilities at hospitals and the practice of making appointments for a number of patients at the same time. Parents who found it possible to do so appeared to take their children to private specialists rather than face these problems at the hospitals. Fourteen parents commented that hospital staff (including medical registrars) and general practitioners were not at all conversant with spina bifida and hydrocephalus, and this resulted in long delays in admissions areas, and other needless anxieties. Several parents, however, added that in the last few years there had been an improvement in their situation. For example, hospital staff now tended to accept a parent's notification of a blocked shunt and begin treatment without a long period of observation.

Shoes and calipers presented problems for several parents. They reported long delays for repairs and long distances to travel to a service. Four parents found difficulty in attending the Ileostomy Association clinic regularly to obtain appliances.

One or two other matters related to the frequent hospitalisation of these children were explored in the parent interviews. These included questions on live-in accommodation at hospitals, the responses of parents and children to separation, parental feelings on admitting their child to hospital, and coping at home on the child's return. These are discussed below.

Parents were asked to assess the value they would place an opportunities to live-in at hospitals when their child was hospitalised. They were almost unanimous in their agreement on the value of such a procedure, 82.3 per cent strongly supporting and 12 per cent giving some support. Parents judged that nearly 60 per cent of the children showed either marked or some reaction to separation. In only 14.6 per cent of cases was no reaction reported.

In respect of parents' reactions, it was reported by over 90 per cent that they experienced considerable reaction to the separations, emphasising the need for support and consideration of the many difficulties experienced by these families in the management of their disabled child. These data should be compared with those reported above on the value parents would place on live-in provisions in hospitals. Both of these important matters are given a prominent place in the recommendations of the Association for the Welfare of Children in Hospital on health care policy relating to children and their families.[2]

However, with this discussion in mind, it is well to consider the general level of satisfaction expressed by parents in relation to the hospital admissions of their children. Some 80.8 per cent of all the parents were satisfied with admissions to hospital for treatment, and only 13.8 per cent reported any degree of dissatisfaction. This information reflects that in a previous section related to medical services generally, but appears to again emphasise the non-medical aspects of hospital services, where more supportive procedures should be implemented.

Finally, parents were asked to indicate how well they coped with their disabled child when the child came home from hospital. Sixty-two (47.7%) reported that they did not experience any problems, and a similar proportion (45.4%) reported that they found care of their child at home initially difficult but then were able to manage. Only 5 parents (3.8%) reported that they were unable to cope.

Recent research into the experiences of families of handicapped children has brought out the difficulties that can be experienced by families in obtaining information and literature on the handicapping condition. The parents interviewed in this study were asked to report on the sources of literature which they have received on spina bifida and hydrocephalus. The data in Table 5.24 clearly show the important role played by the Spina Bifida Association in this area. The Association is a parent group and one of its objectives is the provision of support and advice to fellow parents of spina bifida children. The other notable aspect of the data is the small extent to which professional workers, other than those employed by the Spina Bifida Association, are found by parents to be a source of literature and information on the disability of their child. This is in contrast to the information previously noted, where 58.5 per cent of the parent group reported that medical and other professional persons were available to them for discussion about the child's disability soon after delivery. It would appear, however, that little written information is provided to parents by professional people, compared with verbal information provided during the first days of the child's life.

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[2] See the *Medical Journal of Australia* 2, 2, 1975, Special Supplement.

Table 5.24: **Sources of literature and information**

Sources of literature	*No. of parents*	*Per cent of group*
Spina Bifida Association	80	61.5
Medical and other professional persons	19	14.6
Parent of another SB/H child	4	3.1
Other sources	3	2.3
Not applicable	22	16.9
Missing information	2	1.6
Totals	130	100.0

5.5 SUMMARY

This chapter has reviewed the information provided by 130 parents interviewed about experiences associated with the birth of a spina bifida and/or hydrocephalic child and during their child's later years. The group of parents interviewed was generally representative of the total group of 240 families except that it included a larger proportion of families with a child with spina bifida only and rural families were slightly under-represented in comparison with families living in urban areas. Of the children with spina bifida, 97.3 per cent had had the lesion closed. Of these, 70.3 per cent had undergone this initial surgery in their 1st week of life and 82.0 per cent, within the 1st month. Of the children with hydrocephalus, 93.7 per cent had a shunt inserted to control the hydrocephalus. Of these, 83.0 per cent had undergone this surgery within the first 6 months of life. Nearly 80.0 per cent of children were initially treated in the 2 Brisbane children's hospitals.

The modal ages of the parents of the 240 children and young adults fell within the 26–30 years range. Eighty-seven per cent of the mothers were advised of the birth of their disabled child within 12 hours of the birth; 45 per cent of them were alone when this information was given to them. Fifty-seven per cent reported that opportunity for discussion was not available on receiving the advice, and 26 per cent did not obtain information on the condition experienced by their child or could not recall the event. Some 34 per cent of the mothers reported that they fully understood the information received.

Data on the spina bifida children's first admission to hospital (on transfer for initial surgery) indicates that 45.8 per cent of families were not consulted about the initial surgery. Some 55 per cent of mothers did not hold their child before transfer of the child for surgery, 36.2 per cent were not encouraged to nurse the child in the hospital of first admission and 32 per cent were not involved in daily care of the child during the first admission, although 61 per cent reported they were satisfied overall with their involvement during the initial treatment stage. Fifty-three per cent of the children were in hospital on first admission for periods greater than 4 weeks, and 62.3 per cent of mothers visited their child daily.

Parents generally reported lack of satisfaction with non-medical aspects of hospital services. Their dissatisfaction centred on the difficulties created for parents of a severely handicapped child by the reduced access to services, resulting from their experiences in out-patient and treatment clinics and inadequate parking arrangements. On the other hand, high levels of satisfaction were reported with medical services. There was overwhelming support by the parents of the value of live-in accommodation in hospitals during periods of treatment for parents with a severely disabled child. Ninety-two per cent reported they adjusted with some difficulty to separations from the child and that nearly 70 per cent of the children also reacted significantly to the separations.

The study has further highlighted the small extent to which professional workers provided information and literature to parents about their child's disability, especially written information.

CHAPTER 6

CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS IN REGULAR AND SPECIAL SCHOOLS

6.1 INTRODUCTION

This chapter surveys the data obtained from 55 school principals and the classroom teachers involved with 116 children experiencing spina bifida and/or hydrocephalus in 72 school settings — that is, in regular primary and secondary schools, special schools appropriate to the child's educational needs (integrated settings), and special schools for children with physical disabilities. The integrated special school placements were mostly schools for mildly mentally handicapped children, which may be considered to be an integrated school setting for the children being studied, in that their placement is not dictated by physical disability. From the perspective of these special schools for the mildly intellectually handicapped, the task of teaching a physically handicapped child has many of the same elements of integration which apply to regular schools. The chapter also presents the results of psycho-educational assessments made of these students.

Table 6.1 sets out details of the 72 schools in terms of school type and of the numbers of students in each type of school. It will be noted that 12 pre-schools (19 children) and 7 secondary schools (8 adolescents) are included in this information and in sections of the discussion which follows, even though these children are not included in all sections of the chapter. Information relevant to the pre-school children is included in the section based on the responses of classroom teachers, and that relevant to adolescents and secondary schools, in the sections based on responses from both school principals and teachers. Otherwise, the results reported refer to regular primary schools and special schools only.

Table 6.1: **School principals and teachers providing information: by type of school and number of students(*a*)**

	Schools			*Students*			
Type of school	*No.*		*%*	*No.*		*%*	
Regular pre-school	8	12	11.1	8	19	6.9	16.4
Special pre-school	4		5.5	11		9.5	
State primary school	27	45	37.5	30	49	25.9	42.3
Independent primary school	18		25.0	19		16.4	
State secondary school	3	7	4.2	4	8	3.4	6.8
Independent secondary school	4		5.5	4		3.4	
School for physically handicapped children	4		5.5	35		30.2	
Opportunity school (Mild MH)	3		4.2	4		3.4	
School for deaf children	1		1.4	1		0.9	
Totals	72		100.0	116		100.0	

(*a*) Percentages do not always total 100, due to rounding.

Table 6.2 sets out information on the mean size of the classes in which the children were enrolled. These range from a mean of approximately 9 children in special schools to approximately 32 children in secondary schools. Similar information on the age of the 116 children is given in Table 6.3.

6.2 INFORMATION FROM SCHOOL PRINCIPALS

The general educational problems faced by children with spina bifida and/or hydrocephalus who were attending regular primary or secondary schools, or schools for the mildly mentally handicapped, were examined using questionnaire responses by school administrators. The principals of 55 such schools in which children from the research group were enrolled were surveyed. The questionnaire employed was designed to obtain information on educational provisions, procedures and attitudes related to spina bifida children in integrated schools. In areas in which information was sought there was some deliberate overlap with those contained in the classroom teachers' report. Questions were included on the extent of special provisions with transport, access to buildings, furniture requirements, administrative decisions on the location of the classroom for the spina bifida child, and the choice of class teacher. Information was also collected about the initial agreement to enrol a spina bifida child and on school principals' reactions when assuming charge of a school where a child with spina bifida had already been placed. Opportunities were given for principals to indicate changes in their attitude over a period during which they gained experience in the integration of a physically handicapped child into the regular school under their charge.

Table 6.2: **Mean size of classes in which children were enrolled: by school type**

School type	*No. of children*	*Range of class size*	*Mean*	*SD*
Pre-school	19	7 to 25	13.2	6.5
Primary	49	8 to 48	29.8	6.5
Secondary	8	31 to 34	32.7	1.5
Special	40	5 to 21	9.4	3.3

Table 6.3: **Mean ages of children: by school type**

School type	*No. of children*	*Range of ages (years)*	*Mean*	*SD*
Pre-school	19	2.1 to 5.6	4.7	0.8
Primary	49	5.5 to 12.5	8.7	2.1
Secondary	8	13.4 to 18.7	15.1	1.7
Special	40	5.0 to 15.0	9.8	2.9

Approximately half of the children (53%) in the schools administered by the principals surveyed required special transport arrangements, and parents were responsible for making these arrangements in 80 per cent of cases. In no instance did the school principal or teacher make transport arrangements, and an officer of the Department of Education played a role in arranging transport in only 6 cases.

Building alterations to meet the needs of the children had been made in only 4 schools (7%); in 3 of these the costs had been borne by the Education Department, and in the other, the work was carried out by the parents of the handicapped child. Though few schools had been modified to increase accessibility for physically disabled children, it would seem that more than this number required structural changes, since a further 9 children (16%) were unable to gain access to all necessary school facilities and the principals considered 6 of these children would have benefited from building modifications.

Clearly, however, not all children with spina bifida depend on building modifications to be able to be catered for in regular schools. In many of the present cases, the principals had given careful consideration to the location of classes in which these physically handicapped children were placed, two-fifths of the principals (21) reporting giving such special consideration. These same principals further indicated that classroom location would continue to be important in future years. Two additional principals foresaw the need for classroom selection in future years to meet the needs of the children in their care.

Special furniture was required for 11 children, but had been obtained for only seven. Both parents and school authorities had supplied special furniture.

Another important administrative consideration is the selection of the class teacher for the handicapped child. Nineteen principals (35%) reported that they had given special attention to this matter, and 2 others indicated that selection of a classroom teacher was likely to be important in future years. Eighteen children (33%) were reported to need assistance with moving about the school. In most cases, more than 1 person was involved in providing this assistance, usually teachers, teacher aides and other children.

Forty per cent of the children (22) needed assistance with toileting during the school day. The main person giving this assistance included parents (in 54.5% of cases) and teaching staff (27.2%). The important contribution made by parents in this aspect of school management will be especially noted. Eight of the respondents indicated that more than 1 person provided help with toileting. Teacher aides were mentioned in 3 responses but in no instance was this aspect of management their sole responsibility. In the 2 cases where children assisted, no adult help was given.

Clearly, parents make a major contribution to ensuring that the toileting needs of spina bifida children in regular schools are met, and while a wide range of other persons also provide this assistance, for very few is it part of their 'normal', or expected, role in the school. The provision of toileting assistance is a source of continuing concern since where it is provided by school personnel, it is a private and voluntary arrangement which is liable to change. Parents, already accepting a major responsibility for this aspect of the successful placement of their child in school, may be called on at short notice if co-operative school personnel are no longer available to assist.

Slightly more than half of the principals (30) surveyed had been responsible for enrolling the child concerned in the school. The others had been appointed to leadership of the school after the child had been in attendance for a period.

Those principals who had admitted a child to their school were requested to provide information on the enrolment in order to explore aspects of the decision-making process. In the cases of three-quarters of these children, a parent of the child had approached the school regarding enrolment. In 7 cases (24%) a guidance officer or visiting teacher for handicapped children had made the request. Only 11 (37%) of the 30 principals reported some apprehension prior to the child's enrolment. The major reasons for this apprehension were toileting and access, with the toileting needs of these children being the major aspect to cause concern.

It is interesting to note that only 1 principal stated that he continued to feel some apprehension about the spina bifida child's enrolment in his school, for the reason that problems of access to rooms and facilities seemed insoluble.

Most principals (87%) in fact reported that they did not experience any continuing apprehension, though a greater proportion of those principals who had not made the decision to admit the child expressed some concern. These concerns were generally about a particular child enrolled in a school, rather than any one problem common to all children. The concerns mentioned included learning problems, toileting, access to buildings, teacher work-load and parental attitude.

The knowledge a school principal has of spina bifida is likely to be a major determinant of any anxiety he may have about the handicapped child in his school. In this survey it was determined that 82 per cent of the principals were provided with information about spina bifida. It can be noted that, as with toileting assistance and admission to the school, parents again were taking a major responsibility for this aspect of school placement, contributing information in 53 per cent of cases, although Education Department resource personnel and colleagues of the principal were involved in providing assistance with information in more than half of the cases (62%). It should also be noted that 18.2 per cent of the administrators reported receiving no information on the condition.

The majority of principals (89%) considered the child's present school placement as the most suitable, with only 6 children (11%) being seen as inappropriately placed. Of these, 2 children were considered to be better placed if enrolled in a special school for physically handicapped children and 4 were considered to be more suitable for placement in a school for mildly mentally handicapped children. However, more than half of the principals (56%) considered that additional support in the school was needed to improve the quality of the handicapped child's school experience. This additional support was predominantly sought in the appointment of teacher aides and an expansion of the visiting teacher service, but additional physical resources were also required by some principals (Table 6.4).

Principals were also asked to comment freely on changes in their attitude to integrating physically handicapped children into regular school settings. They were asked specifically if they attributed these changes to their experience of having a spina bifida child in their school. Responses were categorised, and the frequencies for each are given in Table 6.5.

Table 6.4: **Most important additional support needed**

Type of support	*No. of children*	*Per cent of valid cases*	*Per cent of total group (n = 55)*
Expanded visiting-teacher service	7	22.6	12.7
Additional aide assistance	8	25.8	14.6
Access to suitable learning program	4	12.9	7.3
Modification to buildings	6	19.3	10.9
Provision of appropriate furniture	1	3.2	1.8
Provision of paramedical services	2	6.5	3.6
Additional equipment	1	3.2	1.8
Multiple responses	2	6.5	3.6
No additional support required	24	—	43.6
Totals	55	100.0	100.0

The predominant theme of the comments was that integration of children with spina bifida had been beneficial both to the handicapped child and the school community as a whole. It is interesting to note that the most common remark was that the principal has always favoured such integration, and by implication, the experience of having a spina bifida child in the school had not been necessary to bring him to favour integration.

Several principals cautioned against any under-estimation of the extra load placed on the teacher and principal by children with special needs, and 1 principal felt this to be an important consideration in his approval of any request to assist such a child. Two other school administrators believed that decisions needed to be made on an individual basis and they did not support the principle of integration for all spina bifida children, *carte blanche*.

Table 6.5: **Principals' comments on integration of physically handicapped children into regular settings**

Categories of comment	*No. of comments*
Reinforced my previous attitude, favourable to integration	19
Improved the understanding and attitudes of other children	12
Demands extra from the teacher	7
This experience has made me favour integration	5
Demands extra from the principal	4
Previous experience with handicapped children had convinced me of value of integration	4
This child has educated me and the teachers about handicap	3
Valuable to integrate physically handicapped into special schools for mildly mentally retarded(a)	2
Each handicapped child must be considered individually for successful integration	2
Child was so little handicapped, no change was experienced	1
Parent's concern was greater than principal's	1
Opposed to integration because of lack of support and strains on school staff	1

(a) This comment was made by principals of schools for the mildly mentally handicapped.

Little research has been reported on the role of school principals in the integration of handicapped children in regular schools. Anderson & Spain (1977) also note this lack of research, but they tend to assume that headteachers and class teachers share similar attitudes. It seems clear from the present study that principals and teachers have different roles and responsibilities in the integration process, and the effort to secure information from school administrators as well as from teachers seems to have been well expended.

Parent-initiated integration, where it occurs, is likely to be successful, since the parents may try one school after another until a receptive climate is encountered. Nonetheless, integration of children with spina bifida and hydrocephalus does seem to have been facilitated by most of the school principals who were surveyed in this study. Their position as an interface between classroom and community is a very important one. Where children are young on admission to regular school, a high level of acceptance of them by the schools has been found in the present study.

6.3 INFORMATION FROM CLASSROOM ASSESSMENTS AND TEACHER REPORTS

Questionnaires were completed by classroom teachers in 72 schools in which 116 of the disabled children surveyed were enrolled (see Table 6.1). Thirty-five of the children (30.2%) lived in residential facilities associated with schools for the physically handicapped and 81 travelled to school from home daily. Information provided by 55 principals on school transport was reported in the previous section, but additional data, made available by teachers in pre-schools, primary and secondary schools and special schools, are discussed here.

6.3.1 Transport and attendance factors

Transport to and from school

Of the 81 (69.8%) children who travelled to school daily (including pre-school), about one-quarter (19) used special transport (Table 6.6). Another one-quarter of the children (21) used clearly independent means of travel such as public transport, walking or even riding bicycles (2). The use of private cars by these children as transport to school is harder to interpret, since many children who are not handicapped are driven to school by parents or neighbours. Financial assistance with transport costs was provided for one-quarter (21) of the students, with 4 being aided by voluntary organisations and 17 by the State Education Department.

Table 6.6: **Means of travelling to school: 81 students living at home**

Means of travel	*No. of children*		*Per cent of group*	
Public transport	15		18.5	
Special bus	7	19	8.7	23.5
Taxi	12		14.8	
Private car	39		48.2	
Walk	4		4.9	
Other	4		4.9	
Totals	81		100.0	

Although three-quarters (75%) of the children were accompanied to school (50% by parents, 25% by older siblings and friends), 82 per cent were reported as not having problems with getting to school. Nine (11%) children needed assistance with transfer to and from a wheelchair and 4 (4.9%) required lifting. Parents, bus- or taxi-drivers and teacher aides provided assistance to most children, with teachers or peers being involved with transport and movement assistance in only 2 cases.

Teachers rated the school attendance of the subjects attending regular and special schools (excluding pre-schools) as good or average in approximately 95 per cent of cases. Only 4 children had poor attendance. The teachers also categorised the reasons for any absences, indicating that a large proportion of absences, some 57 per cent, related to a child's disability. Only 3 teachers felt the absences of the child in their class were not always justified. On the other hand, 9 teachers believed that the child's poor attendance record adversely affected progress in school.

Special furniture and building modifications

The teachers employed in special schools indicated that 24 children used special desks which had been supplied by the Education Department. Three teachers in regular schools stated that special desks were needed, while 5 indicated that desks of special height were already in use. Three reported the availability of special chairs and 1 described a special tray fitted to a wheelchair. Only one instance of special academic equipment was noted; a child in his first year at a special school used a typewriter, though it was planned to phase out its use as his handwriting improved.

Other than responses from teachers at special schools for the physically handicapped, or at 1 high school in which several physically handicapped students had been enrolled, only 3 responses indicated that structural modifications have been made to regular school buildings. At 1 school for the mildly intellectually handicapped and 1 primary school, ramps had been built and room access improved, while at another primary school a drainage gutter was bridged to permit wheelchair access to the toilets. However, the need for ramps and the bridging of gutters was mentioned by 9 teachers and better toilet facilities by 4 others.

Other suggestions in this area were telescopic crutches for easy storage, exercising equipment appropriate to the physically handicapped, railings in the toilet area, covered walkways to toilet blocks, and changes to toilet area design, especially outward-opening doors.

Mobility and school participation levels

Though a higher proportion of the children in special schools than in regular schools had mobility problems, the majority of the 116 children (76%) were ambulant, but only 4 per cent were regarded as possessing a normal gait (Table 6.7). Ten per cent were reported able to walk or run as well as normal children.

Table 6.7: **Mobility and extent of abnormal gait**

Mobility and gait	*No. of children*		*Per cent*	
Unable to walk	28		24.1	
Able to walk				
Very abnormal gait	32	88	27.6	75.9
Moderately abnormal gait	31		26.7	
Slightly abnormal gait	21		18.1	
No abnormal gait	4		3.5	
Totals	116		100.0	

Almost 15 per cent were able to walk distances without undue difficulty, 25 per cent could do all walking necessary for the school program and a further 10 per cent could walk moderate distances at a reasonable pace. The remaining half of the 116 children were either unable to walk or able to walk only short distances (Table 6.8).

The extent of difficulties experienced by these children with the negotiation of stairs is indicated in Table 6.9. Some teachers were not able to provide this information, and it is possible that some schools were entirely without these obstacles. However, rather more difficulty with using stairs was recorded than for walking, with only 16 per cent of the students managing without difficulty. Another 32 per cent of the children could use stairs slowly without assistance. Twelve per cent needed assistance with negotiating stairs.

Table 6.8: **Ability to walk distances**

Distances walked	*No. of children*	*Per cent*
No difficulty with distance	17	14.7
Manages distances necessary in school	29	25.0
Walks moderate distances at reasonable pace	11	9.5
Walks short distances slowly	26	22.4
Walks only a few steps or not at all	31	26.7
No response	2	1.7
Totals	116	100.0

Table 6.9: **Ability to manage stairs**

Difficulty with stairs	*No. of children*	*Per cent*
No difficulty with stairs	19	16.4
Slow, but manages unaided	37	31.9
Needs assistance	14	12.1
Cannot manage stairs	42	36.2
Missing data	4	3.4
Totals	116	100.0

The extent of the use of aids to mobility is indicated in Table 6.10. One-fifth (20%) of this group of 116 students needed no mobility aids, but the average child who needed mobility aids used two or three forms of assistance; half (52%) of the group had calipers fitted.

Sixty-three per cent required special footwear, and 43 per cent used wheelchairs; though some of these children were not totally dependent on wheelchairs for mobility. However, the information obtained indicated that usage of wheelchairs in school varied considerably. Only 16 per cent of the children used wheelchairs consistently. The less frequent mobility aids recorded in the table for 11 students included a row car, parapodium, walkers and a skateboard.

Of children from Grade 1 upwards (97), 44 per cent were reported by the teachers as not being hindered in their participation in school activities. Among the aspects of curriculum affected by limitations of movement were various sports, physical education, excursions, science studies, library usage, manual arts, and drama and movement classes. Aspects of the curriculum from which children were actually excluded were, typically, physical education, sports and movement classes, but only 2 children did not attend swimming lessons and only 1 did not take part in drama. One child was not able to undertake school excursions if steps would be encountered. In total, however, 36 per cent of the children were excluded from at least some aspect of school curriculum due to poor mobility. Of these, parental prohibition was reported for only 2 children, and the need for safety precautions was mentioned for 3 others. Thirty-two per cent were reported to be excluded from aspects of the curriculum because they were unable to do the activities — a reason which might not stand close inspection. Further information from all teachers, except those in pre-school settings, indicated that only 3 children were excluded from school activities for reasons other than poor mobility. For the 3 cases, this involved exclusion from swimming, contact sports and meals associated with home economics classes because of diet.

Table 6.10: **Use of mobility aids** (*a*)

Mobility aids	*No. of children*	*Per cent of use by 116 children*
Calipers	60	51.7
Elbow crutches	31	26.7
Armpit crutches	10	8.6
Special boots or shoes	73	62.9
Wheelchairs	52	43.1
Other	11	9.5
Total aids	237	
No aids necessary	24	20.7

(*a*) Multiple aids to mobility were used by a number of students.

Physiotherapy

The 90 per cent of teachers who reported children with some degree of ambulatory difficulty were surveyed to determine the extent of physiotherapy services available to these children or utilised by them. Teachers were unaware of the physiotherapy needs (if any) of 13 per cent of the children. About 40 per cent of the children were recorded as receiving physiotherapy treatment, which was provided, about equally, out of school hours, in school hours at a hospital, and at school during school hours, this last category being common in special schools linked to a hospital and/or residential facility. It must also be noted, however, that teacher information indicated that 28 per cent of children might need physiotherapy but were not receiving it (Table 6.11).

Where physiotherapy was being received, it was most commonly arranged more than once a week or on a weekly basis (Table 6.12). Some children were seen monthly or at longer intervals, presumably to monitor such conditions as posture and gait or to change the treatment regime being given regularly by parents, for example.

6.3.2 Manipulative skills

Teachers were asked to identify the presence of a disability of upper limbs or hands. Fifteen per cent of the regular school students and 20 per cent of those at special schools were judged to have some manipulative difficulty. Since only 5 per cent of the children used 1 hand to achieve better stability while sitting, there was little evidence of gross mobility difficulties adversely affecting fine motor skills.

Teacher ratings of difficulty in performing tasks requiring good hand function were fairly uniform over the set of tasks; an average of 61 per cent of the children were judged to have no difficulty (Table 6.13). However, 5 per cent were rated as having severe problems, with proportions ranging from 1 per cent on 'turning pages' to 9 per cent on 'ruling lines' and 11 per cent on 'ball-handling'. An analysis of degree of manipulative difficulty by school placement (regular primary or special school) and by whether a shunt had been inserted was made for 3 tasks — using scissors, ruling lines and writing. This strongly suggested greater difficulty among shunted children in both school situations.

A similar analysis of the teacher's assessment of whether the child was working 'to capacity' was made for several academic topics (Table 6.14). Chi-square tests were performed to examine the relationships between presence or absence of a shunt and teachers' ratings of difficulty for their students in each of the 6 motor tasks. Significantly greater difficulty in using scissors for children with shunts in both regular ($X^2_1 = 5.59$) and special ($X^2_1 = 3.85$) schools was found and for the use of other educational equipment for children in special schools only.

Table 6.11: **Time and place of physiotherapy**

Provision of physiotherapy	*No. of children*	*Per cent*
Physiotherapy not needed	11	9.5
Physiotherapy needed but not received	33	28.4
Physiotherapy provided at schools in school hours	14	12.1
Physiotherapy provided at hospital/therapy centre in school hours	18	15.5
Physiotherapy provided at hospital/therapy centre out of school hours	14	12.1
Teacher unaware	15	12.9
Not applicable	11	9.5
Totals	116	100.0

Table 6.12: **Frequency of physiotherapy(*a*)**

Frequency	*No. of children*	*Per cent*
More than once a week	26 } 34	36.1 } 47.2
Weekly	8	11.1
Monthly or longer intervals	12	16.7
Teacher unaware	15	20.8
No response	11	15.3
Totals	72	100.0

(*a*) Excludes 44 students whose teachers reported physiotherapy was either not needed or not received.

Table 6.13: **Level of difficulty experienced in tasks requiring good hand function: primary- and secondary-age-level children only**

	Level of difficulty											
	None		*Slight*		*Moderate*		*Severe*		*Missing data*		*Totals*	
Manipulative tasks	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Writing	55	56.6	23	23.7	12	12.4	4	4.1	3	3.1	97	100
Drawing	66	68.0	15	15.5	8	8.2	5	5.2	3	3.1	97	100
Using an eraser	69	71.1	9	9.3	5	5.2	4	4.1	10	10.3	97	100
Ruling lines	54	55.6	18	18.6	7	7.2	9	9.3	9	9.3	97	100
Steadying paper	67	69.0	17	17.5	6	6.2	2	2.1	5	5.2	97	100
Taking books from desk	67	69.0	13	13.4	5	5.2	3	3.1	9	9.3	97	100
Turning pages	76	78.3	12	12.4	4	4.1	0	0	5	5.2	97	100
Using scissors	56	57.7	16	16.5	14	14.4	5	5.2	6	6.2	97	100
Craft activities	53	54.6	22	22.7	11	11.3	5	5.2	6	6.2	97	100
Handling equipment	57	58.8	22	22.7	7	7.2	3	3.1	8	8.2	97	100
Ball handling	35	36.1	24	24.7	18	18.6	11	11.3	9	9.3	97	100
Means		61.4		17.9		9.1		4.8		6.8	97	100

However, since the pattern of most results for the remaining tasks was similar (that is, children with shunts experienced greater difficulty), the data were combined for regular and special schools and Chi-square tests again performed. The tests were significant only for use of scissors ($X^2_1 = 11.34$) and craft skills ($X^2_1 = 3.85$). In summary, the data indicate consistent difficulty in the use of scissors for children with shunts and suggest some difficulty with craft skills and a range of other educational equipment items, but no differences for ruling lines, writing or ball-handling.

Chi-square tests were also performed to investigate the relationship between teachers' ratings of difficulty and school placement. Significant relationships were observed only for ruling lines ($X^2_1 = 10.39$; $p<.01$) and writing ($X^2_1 = 4.59$; $p<.05$).

An analysis of the extent of help offered by other children indicated that, while this was frequent — in 45 per cent of cases — only 4 per cent of children were seen as being helped too often. No students were cited as being excluded from curriculum subjects as a result of manipulative difficulties. However, teachers did make some allowances for students, usually by giving extra time in tests or excusing poor handwriting. More than half of the children were regarded as not needing special instructional adaptation, but 18 per cent were given extra individual attention.

6.3.3 Aspects of self-care

Continence

Teachers' reports of the degree of continence of bowel and bladder for the 116 children are presented in Table 6.15. It will be noted that only 19.8 per cent of subjects are continent of bladder, while more than half (54%) are continent of bowel. Generally more incontinence is found in special schools, although these difficulties are still substantial in regular schools where, for example, 66 per cent of the 65

Table 6.14: **Relationship between presence/absence of shunt and difficulty with fine motor tasks(*a*)**

	Children in regular school		*Children in special school*		*Children in regular and special schools*	
Task	*No difficulty*	*Difficulty*	*No difficulty*	*Difficulty*	*No difficulty*	*Difficulty*
(a) Scissors						
No shunt	18	2	11	4	29	6
Shunt	12	11	9	16	21	27
	(X^2_1 = 5.57; <.05)		(X^2_1 = 3.85; <.05)		(X^2_1 = 11.34; <.01)	
(b) Ruling lines						
No shunt	13	3	9	6	22	9
Shunt	20	6	6	16	26	22
	(X^2_1 = 0.003; ns)		(X^2_1 = 2.72; ns)		(X^2_1 = 1.58; ns)	
(c) Writing						
No shunt	12	3	10	5	22	8
Shunt	19	10	8	17	27	27
	(X^2_1 = 0.42; ns)		(X^2_1 = 3.26; ns)		(X^2_1 = 3.41; ns)	
(d) Ball-handling						
No shunt	7	8	9	6	16	14
Shunt	10	16	7	16	17	32
	(X^2_1 = 0.03; ns)		(X^2_1 = 2.16; ns)		(X^2_1 = 1.95; ns)	
(e) Craft skills						
No shunt	11	3	11	4	22	7
Shunt	17	11	10	15	27	26
	(X^2_1 = 0.66; ns)		(X^2_1 = 2.95; ns)		(X^2_1 = 3.85; <.05)	
(f) Other educ. equipment						
No shunt	10	4	13	2	23	6
Shunt	19	9	11	12	30	21
	(X^2_1 = 0.01; ns)		(X^2_1 = 4.34; <.05)		(X^2_1 = 2.61; ns)	

(*a*) The numbers in the contingency tables differ as some teachers did not rate their pupils on all items.

Table 6.15: **Teachers' reports of children's incontinence of bowel and bladder: by type of school**

	Regular schools		*Special schools*		*All children*	
Type and level of continence	*No.*	*%*	*No.*	*%*	*No.*	*%*
Bladder						
Continent	19	29.2	4	7.8	23	19.8
Occasional incontinence	43	66.2	43	84.4	86	74.2
Incontinent	3	4.6	4	7.8	7	6.0
Totals	65	100.0	51	100.0	116	100.0
Bowel						
Continent	47	72.3	16	31.4	63	54.3
Occasional incontinence	11	16.9	20	39.2	31	26.7
Incontinent	7	10.8	15	29.4	22	19.0
Totals	65	100.0	51	100.0	116	100.0

children studied experienced occasional incontinence of the bladder. Table 6.16[1] indicates the need for assistance in toileting for special school students, and relates this assistance to age level and ambulation. It will be noted that severe problems with ambulation dominate this group at each age level and that toileting assistance is more necessary with younger than older children. Some 66 per cent of the pre-school children needed complete toileting assistance, while a similar proportion of the secondary age level group had no need for such help.

A little more than two-thirds (68.1%) of the 116 subjects used urine collection apparatus. Approximately one-quarter (24.1%) wore protective apparatus for incontinence of the bowel. A wide range of persons provide toileting assistance to the group (Table 6.17). Apart from those subjects in schools with residential provision attached, where nursing aides are available to help with toileting, parents were the major group providing this assistance, followed by teachers and teacher aides. It should be noted that Table 6.17 is based on data provided by teachers, including those of children in special schools for the physically handicapped. Earlier in this chapter school principals provided similar information on toileting, but this was confined to children in integrated placement. However, the general pattern of assistance provided is similar in the 2 sets of information.

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[1] In Table 6.16 and a number of following tables, school age levels are used to indicate the length of schooling undertaken by the students. The categories used are pre-school (1 or 2 years before primary school start), junior (Years 1 and 2), middle years (Years 3, 4 and 5) and senior (Years 6 and 7). Secondary refers to years of schooling beyond the last year of primary school (Years 8, 9 and 10).

Table 6.16: **Degree of help in toileting by school-age level and ambulation difficulties: children in special schools**(*a*)

Ambulation difficulties(*b*)		*Pre-school*		*Junior school*		*Middle school*		*Senior school*		*Secondary*		*All children*
		Severe	*Mild*	*Severe*	*Mild*	*Severe*	*Mild*	*Severe*	*Mild*	*Severe*	*Mild*	
No help in toileting	*No.*					2	2	3		7		14
	%					16.7	16.7	50.0		70.0		(27.5)
A little help	*No.*	3		4	1	1		1		2		12
	%	33.3		28.6	7.1	8.3		16.7		20.0		(23.5)
Needs complete toilet assistance	*No.*	6		8	1	6	1	2		1		25
	%	66.7		57.2	7.1	50.0	8.3	33.3		10.0		(49.0)
Totals	*No.*	9		12	2	9	3	6		10		51
	%	100.0		85.8	14.2	75.0	25.0	100.0		100.0		(100.0)

(*a*) Percentages are for each school-age level, except those in parentheses, which are for the total group.
(*b*) Severe ambulation difficulties includes children unable to walk. The mild category includes children with no ambulation problems.

Table 6.17: **Persons involved in provision of help for incontinence**

Provider of help	*Incontinence of bladder*		*Incontinence of bowel*	
	No. of children	*%*	*No. of children*	*%*
Teacher	6	5.2	5	4.3
Teacher aide	5	4.3	5	4.3
Parent	12	10.3	9	7.7
Pupil	1	0.9	1	0.9
Nursing aide from residential	29	25.0	27	23.2
Blue nurse	2	1.7	1	0.9
Parent and other persons	1	0.9	—	—
Teacher and teacher aide	4	3.4	1	0.9
Help not needed	54	46.6	61	52.6
Missing data	2	1.7	6	5.2
Totals	116	100.0	116	100.0

Eating

Only 1 child in a regular school and 3 children in special schools were noted to need assistance with eating at school, 1 of these experiencing cerebral palsy as well as spina bifida. It is not known what proportion of the children who go home or return to residential facilities for lunch need assistance with eating. Assistance in this aspect in the special schools was given by the teacher or teacher aide, and in the case of the specific child referred to above, a speech therapist.

Dressing

Help with dressing was much more frequent among the special school children (82.4%) than the regular class children (29.2%). With special school children, this need for assistance appeared to be mostly associated with degree of ambulatory capacity, as is evident from Table 6.18. However, the age-related trend in the need for assistance with toileting is less strong in the case of dressing, with at least 60 per cent of subjects at each school age level with severe ambulation problems and a need for assistance with dressing.

6.3.4 Speech, vision and hearing

Teacher assessments of presence or absence of defective speech in the children, and the extent of speech defects where they occurred, indicated that 74.1 per cent did not present with speech problems. Of the remainder, most were recorded as having mild forms of defective speech, with only 6 children (11.8%) listed as having a severe defect.

A comparison of children in regular and special schools indicated that 88 per cent in regular schools were free of speech difficulties, but only 57 per cent of special school children were thought not to need speech therapy, with 31 per cent having mild defects. Although a total of 9 per cent of all children were said to receive speech therapy either at school, privately or at a clinic, 17 per cent were judged to need therapy but did not receive it.

Table 6.18: **Help needed with dressing by school-age level and ambulation difficulties: children in special schools**(*a*)

Ambulation difficulties(*b*)		*Pre-school*		*Junior school*		*Middle school*		*Senior school*		*Secondary*		*All children*
		Severe	*Mild*	*Severe*	*Mild*	*Severe*	*Mild*	*Severe*	*Mild*	*Severe*	*Mild*	
No help needed	*No.*				1	1	1		2	4		9
	%				7.1	8.3	8.3		33.3	40.0		(17.6)
Help needed with dressing	*No.*	9		12	1	8	2		4	6		42
	%	100.0		85.7	7.1	66.7	16.7		66.7	60.0		(82.4)
Totals	*No.*	9		12	2	9	3		6	10		51
	%	100.0		85.8	14.2	75.0	25.0		100.0	100.0		(100.0)

(*a*) Percentages are for each school-age level, except those in parentheses, which are for the total group.

(*b*) Severe ambulation difficulties includes children unable to walk. The mild category includes children with no ambulation problems.

Hearing impairment was noted for only 4 children (3%), 2 each in regular and special schools (Table 6.19). Only 1 had a hearing-aid. Problems with vision were noted by teachers more frequently, with some 18 per cent assessed as having an impairment. Thirteen per cent (15 students) wore glasses, though it was reported that most of these had poor vision even when wearing spectacles. Visual problems were more prevalent in special schools (24%) than in regular schools, where only 14 per cent of those enrolled were so identified.

6.3.5 Cognitive skills

The intellectual development of the school-age children was assessed using the Revised Wechsler Intelligence Scale for Children (WISC-R) (Wechsler 1974). The age range of the group of 73 children for whom WISC-R results were obtained was from 6 years to 15 years 1 month, with a mean CA of 9 years 11 months. In addition, assessments were made of 32 younger children employing the Wechsler Pre-school and Primary Scale of Intelligence (WPPSI) (Wechsler 1967), giving a total of 105 students. An analysis of the grade levels, diagnosis and sex of these children and adolescents is given in Table 6.20.

Table 6.21 sets out results for these 2 groups of children. Mean WISC-R I.Q.s for the group of children are shown, with mean verbal, performance and full-scale I.Q.s of 84.5, 79.7 and 80.7 respectively. Mean WPPSI for the 32 young children were 96.2, 86.4 and 90.7 respectively. The downward trend of the distributions, especially for the older group, will be noticed. When both groups are combined[2], half (50.5%) of the 105 children have I.Q.s below or equal to I.Q. 84.

These results are illustrated in Figure 6.1, which portrays the I.Q. distributions for the 105 children superimposed on the normal curve and clearly shows the flattening of the distribution.

Table 6.19: **Teachers' assessments of children's impairment of hearing and vision: by school type**

	Regular school		*Special school*		*All children*	
Impairment	*No.*	*%*	*No.*	*%*	*No.*	*%*
Hearing						
Hearing impaired	2	3.1	2	3.9	4	3.4
Hearing not impaired	63	96.9	49	96.1	112	96.6
Totals	65	100.0	51	100.0	116	100.0
Vision						
Vision impaired	9	13.8	12	23.5	21	18.1
Vision not impaired	55	84.6	38	74.5	93	80.2
Missing data	1	1.5	1	2.0	2	1.7
Totals	65	100.0	51	100.0	116	100.0

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[2] Since the WPPSI and WISC-R have a similar theoretical rationale, and since each is designed to cover different age ranges with appropriate and mostly corresponding item types in the subtest, it was felt that the combination of Verbal, Performance and Full-Scale I.Q.s was justified.

An analysis of the WISC-R I.Q. scores by grade groupings and type of school (Table 6.22) indicated that, as would be expected, children in regular schools tended to have more 'normal' results, while those in special schools scored somewhat lower. The mean verbal I.Q. of 39 regular school children was 97.1, but only 70.1 for those in special schools. The often-noted superiority of Verbal (97.1) over Performance (88.1) I.Q. was much more noticeable among special school children (V = 70.1, P = 69.4).

An analysis of the WISC-R results by type of school placement and the diagnostic sign of shunt/no shunt revealed a slight intellectual superiority of children without shunts over those with shunts (Table 6.23). It is interesting to note that as with children enrolled in special schools, the verbal–performance discrepancy was much more noticeable among the children with shunts. A consistent, though not marked, superiority of boys over girls was also noted (Table 6.24), especially among special school children.

Figure 6.1: **Distribution of IQ scores for 105 children with spina bifida and hydrocephalus**

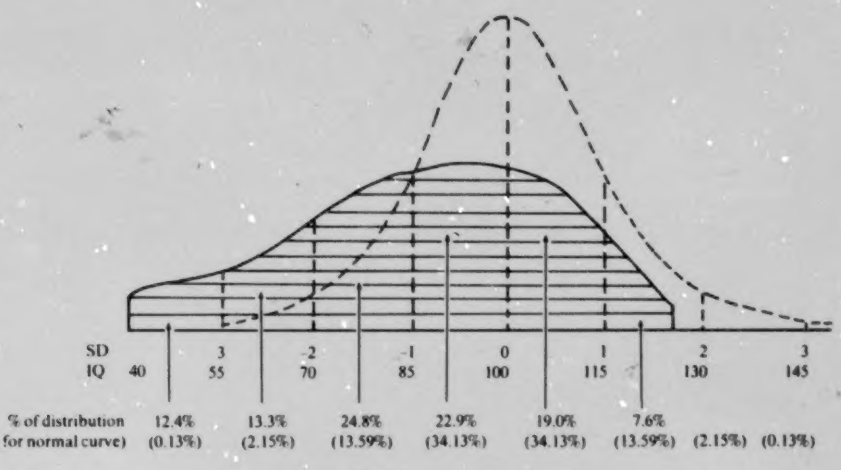


Table 6.20: **Year of schooling, diagnosis and sex for the 105 students**

Spina bifida only				*S.B./H., no shunt*			*S.B./H., with shunt*			*H. only, with shunt*			*All students*		
Grade	*Males*	*Females*	*Total*	*Males*	*Females*	*Total*	*Males*	*Females*	*Total*	*Males*	*Females*	*Total*	*Males*	*Females*	*Total*
10	1		1					1	1				1	1	2
9		1	1	2		2							2	1	3
8	1		1				3	3	6				4	3	7
7	2	2	4					3	3		1	1	2	6	8
6	3	1	4	1	1	2	2		2	1		1	7	2	9
5	1	2	3		2	2	2	1	3	1	1	2	4	6	10
4		2	2				4	4	8				4	6	10
3	3		3	1		1	2	5	7	1		1	7	5	12
2	1	1	2	1	1	2	4	4	8	1	1	2	7	7	14
1		1	1		1	1	8	4	12				8	6	14
P		1	1				3	4	7	1		1	4	5	9
K	2		2	1	1	2	1	1	2		1	1	4	3	7
Totals	14	11	25	6	6	12	29	30	59	5	4	9	54	51	105

Table 6.21: **Intelligence test scores for 105 children with spina bifida and/or hydrocephalus**

		WISC-R		*WPPSI*		*Totals*		
I.Q. ranges	*SD*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*Cum. %*
115–129	+2	3	4.1	5	15.6	8	7.6	100.0
100–114	+1	15	20.6	5	15.6	20	19.0	92.4
85–99	−1	13	17.8	11	34.4	24	22.9	73.4
70–84	−2	21	28.7	5	15.6	26	24.8	50.5
55–69	−3	10	13.7	4	12.5	14	13.3	25.7
40–54	−4	11	15.1	2	6.3	13	12.4	12.4
Totals		73	100.0	32	100.0	105	100.0	100.0

	WISC-R		*WPPSI*	
Mean Verbal I.Q.	(n = 73)	84.5	(n = 32)	96.2
Mean Performance I.Q.	(n = 73)	79.7	(n = 32)	86.4
Mean Full-Scale I.Q.	(n = 73)	80.7	(n = 32)	90.7

Table 6.22: **Mean WISC-R I.Q. of children, by school placement and school-age level**

	Junior primary		*Middle primary*		*Senior primary*		*Secondary*		*All children*	
Test	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school										
Chronological age	7.0	5	8.8	21	11.4	12	12.6	1	9.5	39
Verbal I.Q.	97.0	5	94.0	21	101.3	12	113.0	1	97.1	39
Performance I.Q.	83.4	5	89.6	21	89.3	12	90.0	1	88.7	39
Full-Scale I.Q.	90.0	5	91.3	21	95.1	12	102.0	1	92.6	39
Special school										
Chronological age	7.2	5	9.0	12	11.3	6	13.3	11	10.5	34
Verbal I.Q.	73.2	5	67.4	12	76.0	6	68.3	11	70.1	34
Performance I.Q.	77.2	5	67.8	12	69.8	6	67.4	11	69.4	34
Full-Scale I.Q.	73.0	5	64.8	12	70.8	6	65.0	11	67.1	34
Totals										
Chronological age	7.1	10	8.9	33	11.4	18	13.3	12	10.0	73
Verbal I.Q.	85.2	10	84.3	33	92.8	18	72.0	12	84.5	73
Performance I.Q.	80.3	10	81.7	33	82.8	18	69.3	12	79.7	73
Full-Scale I.Q.	81.5	10	81.7	33	87.0	18	68.1	12	80.7	73

Table 6.23: **Mean WISC-R I.Q. of children: by school placement and presence of shunt(*a*)**

	No shunt		*Shunt*		*All children*	
School type and test scales	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school						
Chronological age	9.7	14	9.2	23	9.4	37
Verbal I.Q.	96.4	14	95.7	23	95.9	37
Performance I.Q.	94.4	14	86.2	23	89.3	37
Full-Scale I.Q.	95.0	14	90.5	23	92.2	37
Special school						
Chronological age	11.1	15	10.1	19	10.5	34
Verbal I.Q.	74.5	15	66.6	19	70.1	34
Performance I.Q.	78.4	15	62.3	19	69.4	34
Full-Scale I.Q.	74.6	15	61.3	19	67.1	34
Totals						
Chronological age	10.4	29	9.6	42	10.0	71
Verbal I.Q.	85.1	29	82.5	42	83.5	71
Performance I.Q.	86.1	29	75.4	42	79.7	71
Full-Scale I.Q.	84.4	29	77.3	42	80.2	71

(a) Two children were omitted because reliable information on shunting was not available.

Table 6.24: **Mean WISC-R I.Q. of children, by school placement and sex**

	Males		*Females*		*All children*	
School type and test scales	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school						
Chronological age	9.5	19	9.5	20	9.5	39
Verbal I.Q.	99.8	19	94.6	20	97.1	39
Performance I.Q.	87.5	19	90.0	20	88.7	39
Full-Scale I.Q.	93.5	19	91.7	20	92.6	39
Special school						
Chronological age	10.4	18	10.1	16	10.5	34
Verbal I.Q.	73.9	18	65.8	16	70.1	34
Performance I.Q.	71.7	18	66.8	16	69.4	34
Full-Scale I.Q.	70.6	18	63.3	16	67.1	34
Totals						
Chronological age	10.0	37	10.0	36	10.0	73
Verbal I.Q.	87.2	37	81.8	36	84.5	73
Performance I.Q.	79.8	37	79.7	36	79.7	73
Full-Scale I.Q.	84.4	37	79.1	36	80.7	73

Table 6.25: **Mean WISC-R subtest–scaled scores and verbal, performance and full-scale I.Q. scores: school-age children**

Subtests/test scales	*Means*	*SD*	*No. of children*
Information	7.6	4.1	73
Similarities	7.3	3.8	73
Arithmetic	7.2	4.0	73
Vocabulary	8.1	4.1	73
Comprehension	7.2	3.6	73
Digit Span	7.4	3.5	64
Picture Completion	7.8	3.3	73
Picture Arrangement	7.0	4.1	73
Block Design	7.2	3.4	73
Object Assembly	7.6	3.3	68
Coding	5.2	3.0	73
Verbal I.Q.	84.5	21.8	73
Performance I.Q.	79.7	18.6	73
Full-Scale I.Q.	80.7	20.5	73

Table 6.25 provides details of the mean scores obtained by the group of 73 children on the WISC-R subtests. It will be noted that the mean subtest-scaled scores were generally close to 7.5, except in Coding which is somewhat lower at 5.2. Perhaps the fine motor co-ordination component of the Coding subtest depressed this score. The low score on Coding deserves some comment in view of the reported difficulties with fine motor co-ordination among children with spina bifida. Table 6.26 indicates that difficulty with the Coding subtest applies generally across age groups, though it may be more pronounced among the children in special schools.

As has already been indicated, 32 children aged from 4 years 0 months to 6 years 5 months were assessed with the Wechsler Pre-school and Primary Scale of Intelligence (WPPSI). These children also showed a slight superiority of Verbal I.Q. (96.2) over Performance I.Q. (86.4) with a Full-Scale I.Q. of 90.7 (Table 6.27). Other than the 'expected' verbal–performance discrepancy, no obvious pattern of subtest scores could be detected within the total group. Breakdowns of the results by school placement, years of schooling, presence of shunt, and sex were performed. Although the numbers of children per sub-group were now quite small, the pattern of scores parallels that observed with the WISC, except that the verbal performance I.Q. discrepancy was close to 10 points for all groups, other than those in special pre-schools. Intelligence quotient scores were higher among children without shunts, except for those in special pre-school placement.

6.3.6 Psycholinguistic skills

Scores on the Illinois Test of Psycholinguistic Abilities (ITPA) were obtained for 71 school-age children, except for the 2 supplementary tests, on which fewer children were assessed. This group of children ranged from 4 years 0 months to 10 years 2 months, with a mean CA of 7 years 0 months.

As with the results reported from measures of intellectual ability, there was a generally lower than normal performance. The average psycholinguistic age of 6 years 2 months was 10 months less than the mean chronological age. These results

Table 6.26: **Mean WISC-R subtest-scaled scores of children: by school placement and school-age level**

School type and subtests	*Junior primary*		*Middle primary*		*Senior primary*		*Secondary*		*All children*	
	Means	*No.*	*Means*	*No.*	*Means*	*No.*	*Means*	*No.*	*Means*	*No.*
Regular school										
Information	9.2	5	9.4	21	10.6	12	13.0	1	9.8	39
Similarities	10.0	5	8.3	21	9.6	12	10.0	1	9.0	39
Arithmetic	8.6	5	9.0	21	10.3	12	14.0	1	9.5	39
Vocabulary	11.0	5	10.0	21	10.5	12	14.0	1	10.5	39
Comprehension	9.2	5	8.4	21	10.3	12	10.0	1	9.1	39
(Digit Span)	7.6	5	9.3	17	9.3	9	12.0	1	9.1	32
Picture Completion	7.8	5	9.2	21	9.7	12	9.0	1	9.2	39
Picture Arrangement	7.4	5	8.7	21	9.3	12	12.0	1	8.8	39
Block Design	7.8	5	9.2	21	7.9	12	9.0	1	8.6	39
Object Assembly	6.8	5	8.5	17	8.7	12	7.0	1	8.2	35
Coding	7.6	5	6.5	21	6.8	12	6.0	1	6.7	39
Special school										
Information	5.4	5	5.1	12	6.3	6	5.1	11	5.3	34
Similarities	4.4	5	4.6	12	7.2	6	5.5	11	5.3	34
Arithmetic	5.6	5	4.6	12	4.8	6	4.2	11	4.6	34
Vocabulary	7.2	5	5.1	12	5.7	6	4.4	11	5.3	34
Comprehension	4.8	5	4.5	12	6.5	6	5.2	11	5.1	34
(Digit Span)	6.0	5	5.0	12	7.6	5	5.6	10	5.8	32
Picture Completion	8.0	5	6.0	12	6.5	6	5.7	11	6.3	34
Picture Arrangement	5.0	5	4.6	12	5.2	6	5.2	11	5.0	34
Block Design	7.6	5	5.6	12	5.5	6	4.9	11	5.6	34
Object Assembly	7.4	5	7.0	12	6.7	6	6.6	10	6.9	33
Coding	5.2	5	2.8	12	3.8	6	3.6	11	3.6	34

are given for school placement and school age levels in Table 6.28. The results by school placement and presence or absence of a shunt are set out in Table 6.29; by sex, in Table 6.30. An analysis of the mean scores on each subtest of the ITPA are set out in Tables 6.31 and 6.32. It was noted that while some 50 per cent of the group were aged up to 6 years, approximately the same proportion had psycholinguistic ages up to only 5 years. These overall results are illustrated in Figure 6.2.

Subtests which were at the normative level for the total group were Manual Expression and Grammatic Closure. However, the apparently superior performance on Sound Blending, and the low score on Auditory Closure, need to be interpreted in the light of similar trends among Australian children (Elkins 1976).

Table 6.27: **Mean WPPSI subtest results and verbal, performance and full-scale I.Q. scores: pre-school and junior children**

Subtests and test scales	*Mean*	*SD*	*No. of children*
Verbal			
Information	9.9	3.5	32
Similarities	10.1	3.8	32
Arithmetic	8.7	3.4	32
Vocabulary	10.4	3.9	32
Comprehension	8.0	3.9	32
Sentences	8.8	3.2	18
Performance			
Picture Completion	8.8	3.2	32
Animal House	7.5	2.9	31
Block Design	8.1	2.9	32
Geometric Design	7.8	3.5	32
Animal House Retest	7.0	2.6	3
Mazes	7.7	3.0	31
Verbal I.Q.	96.2	19.9	32
Performance I.Q.	86.4	17.1	32
Full-Scale I.Q.	90.7	19.6	32

Table 6.28: **Mean ITPA psycholinguistic age of children: by school placement and school age level**

	Pre-school		*Junior primary*		*Middle primary*		*All children*	
School placement	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular								
Chronological age	4.9	14	6.2	18	8.8	20	6.8	52
Psycholinguistic age	4.5	14	6.0	18	7.9	20	6.3	52
Special								
Chronological age	5.0	1	6.7	9	8.7	9	7.6	19
Psycholinguistic age	6.0	1	5.2	9	6.5	9	5.8	19
Totals								
Chronological age	4.9	15	6.4	27	8.8	29	7.0	71
Psycholinguistic age	4.6	15	5.7	27	7.5	29	6.2	71

Table 6.29: **Mean ITPA psycholinguistic ages of children: by school placement and presence of shunt(*a*)**

	No shunt		Shunt		All children	
School placement	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular pre-school						
Chronological age	5.1	5	4.9	11	5.0	16
Psycholinguistic age	4.5	5	4.4	11	4.4	16
Regular primary						
Chronological age	8.1	10	7.6	25	7.7	35
Psycholinguistic age	7.6	10	7.2	25	7.3	35
Special (pre-school and primary)						
Chronological age	8.2	4	7.4	15	7.6	19
Psycholinguistic age	7.0	4	5.5	15	5.8	19
Totals						
Chronological age	7.4	19	6.9	51	7.0	70
Psycholinguistic age	6.7	19	6.1	51	6.2	70

(*a*) A confirmed diagnosis as to shunt was not available for 1 regular pre-school child.

Table 6.30: **Mean ITPA psycholinguistic ages of children: by school placement and sex**

	Males		Females		All children	
School placement	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular pre-school						
Chronological age	5.1	7	5.0	10	5.0	17
Psycholinguistic age	4.9	7	4.0	10	4.4	17
Regular primary						
Chronological age	7.5	17	7.9	18	7.7	35
Psycholinguistic age	7.2	17	7.4	18	7.3	35
Special (pre-school and primary)						
Chronological age	7.6	13	7.6	6	7.6	19
Psycholinguistic age	5.9	13	5.6	6	5.8	19
Totals						
Chronological age	7.1	37	7.0	34	7.0	71
Psycholinguistic age	6.3	37	6.1	34	6.2	71

No clear pattern of strengths or weaknesses could be detected in these results across the ITPA model dimensions based on channel of communication, level of processing and type of process. As with I.Q., there was a tendency for children placed in regular schools to perform better than those in special schools. In addition, no clear pattern emerged to contrast children with and without shunts, each group appearing to have similar discrepancies between chronological age and psycholinguistic age. Scores of boys and girls were also very similar in this group of spina bifida and hydrocephalic children.

6.3.7 Academic achievement

Standardised measures

The academic achievement of 78 children in primary school grade levels, at both regular and special schools, and those of secondary school age attending special schools, were assessed using the St. Lucia Graded Word Reading Test (Andrews 1969), the Passage Comprehension subtest of the Woodcock Reading Mastery Tests (Woodcock 1973), the Schonell Spelling Test (Schonell & Schonell 1950) and the appropriate level of the Moreton Mathematics Tests (Andrews, Elkins & Cochrane 1971). The results on all tests are expressed in age-equivalent scores in Table 6.33. Assessments were not possible on each test for all 78 children and adolescents and the respective numbers of subjects in each case will be noted in tables.

Children placed in regular schools achieved fairly normal progress in that they tended to score at about their chronological ages on most tests. Some slightly lower mean scores were noted in spelling and mathematics, but overall — intellectual level considered also — the academic achievement of this group was as would be expected from the regular school population. Among those children in special schools, the picture is quite different; however, the poorer academic achievement scores are also commensurate with the lower intellectual level observed among the special school children.

Table 6.31: **Mean ITPA subtest results: age scores and scaled scores**

Subtests	*Age scores*		*Scaled scores*		*No. of children*
	Mean	*SD*	*Mean*	*SD*	
Auditory Reception	6:5	2:2	33.1	8.4	71
Visual Reception	6:0	1:1	30.9	7.9	71
Auditory Association	6:8	2:1	33.2	11.2	71
Visual Association	6:0	2:2	30.1	10.2	71
Verbal Expression	5:7	1:8	31.3	7.0	71
Manual Expression	7:2	2:5	36.4	7.5	71
Grammatic Closure	7:0	2:2	35.4	11.5	71
Visual Closure	5:4	2:0	27.4	7.9	71
Auditory Sequential Memory	6:1	2:6	33.8	8.0	71
Visual Sequential Memory	6:0	2:4	30.8	9.1	71
Auditory Closure	6:0	2:1	30.9	7.8	63
Sound Blending	7:4	1:8	42.8	10.9	64

An analysis of academic achievement, based on presence or absence of a shunt (Table 6.34), indicates little difference in scores on this basis among regular school children, but in special schools the children with shunts have achievement levels much closer to their chronological age than those without shunts. Differences in performance between boys and girls were mostly small, boys tending to achieve slightly better scores in reading and girls, slightly better in mathematics (Table 6.35). Since both of these trends are the opposite of what might be expected among non-handicapped children, it is difficult to interpret this finding. However, as girls with spina bifida and/or hydrocephalus in our sample had slightly lower verbal I.Q. (see Table 6.24), the above effects may well be accounted for.

Table 6.32: **Mean ITPA subtest–scaled scores of children: by school placement and school-age level**

School placement and subtests	*Pre-school*		*Junior primary*		*Middle primary*		*All children*	
	Mean	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school								
Pre-school								
Auditory Reception	34.9	14	24.0	3			32.9	17
Visual Reception	32.6	14	28.0	3			31.8	17
Visual Memory	32.4	14	21.7	3			30.5	17
Auditory Association	35.8	14	15.3	3			32.2	17
Auditory Memory	34.8	14	24.7	3			33.0	17
Visual Association	30.3	14	17.3	3			28.0	17
Visual Closure	27.7	14	19.7	3			26.3	17
Verbal Expression	34.2	14	24.3	3			32.5	17
Grammatic Closure	38.4	14	20.6	3			35.3	17
Manual Expression	37.7	14	25.3	3			35.5	17
Auditory Closure	29.8	12	21.7	3			28.2	15
Sound Blending	42.0	13	38.0	3			41.3	16
Primary								
Auditory Reception			39.0	15	33.0	20	35.7	35
Visual Reception			34.9	15	31.6	20	33.0	35
Visual Memory			33.1	15	33.5	20	33.3	35
Auditory Association			39.9	15	35.0	20	37.1	35
Auditory Memory			34.3	15	37.0	20	35.8	35
Visual Association			35.2	15	32.1	20	33.4	35
Visual Closure			30.6	15	29.1	20	29.7	35
Verbal Expression			37.3	15	29.1	20	32.6	35
Grammatic Closure			43.1	15	36.4	20	39.3	35
Manual Expression			38.3	15	36.5	20	37.3	35
Auditory Closure			34.8	13	33.5	17	34.1	30
Sound Blending			54.2	13	42.1	17	47.4	30
Special school								
Auditory Reception	50.0	1	27.9	9	26.7	9	28.5	19
Visual Reception	39.0	1	27.7	9	23.8	9	26.4	19
Visual Memory	42.0	1	25.1	9	26.0	9	26.4	19
Auditory Association	43.0	1	28.0	9	23.8	9	26.8	19
Auditory Memory	42.0	1	28.9	9	31.3	9	30.7	19
Visual Association	43.0	1	25.9	9	24.6	9	26.2	19
Visual Closure	27.0	1	26.3	9	22.2	9	24.4	19
Verbal Expression	35.0	1	27.8	9	26.9	9	27.7	19
Grammatic Closure	52.0	1	29.6	9	24.1	9	28.1	19
Manual Expression	45.0	1	35.1	9	35.0	8	35.6	18
Auditory Closure	37.0	1	28.7	9	26.4	8	28.1	18
Sound Blending	66.0	1	32.4	9	37.9	8	36.7	18
Totals								
Auditory Reception	35.9	15	33.6	27	31.2	29	33.1	71
Visual Reception	33.0	15	31.7	27	29.1	29	30.9	71
Visual Memory	33.1	15	29.1	27	31.2	29	30.8	71

School placement and subtests	*Pre-school*		*Junior primary*		*Middle primary*		*All children*	
	Mean	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Auditory Association	36.3	15	33.2	27	31.5	29	33.2	71
Auditory Memory	35.3	15	31.4	27	35.2	29	33.8	71
Visual Association	31.1	15	30.1	27	29.7	29	30.2	71
Visual Closure	27.7	15	28.0	27	26.9	29	27.5	71
Verbal Expression	34.3	15	32.7	27	28.4	29	31.3	71
Grammatic Closure	39.3	15	36.1	27	32.6	29	35.4	71
Manual Expression	38.2	15	35.8	27	36.1	28	36.4	70
Auditory Closure	30.4	13	31.0	25	31.2	25	31.0	63
Sound Blending	43.7	14	44.4	25	40.8	25	42.8	64

Teachers' assessments

The class teachers of the 97 primary and secondary age-level children enrolled in regular and special schools were requested to assess the school performance of the spina bifida/hydrocephalic children they taught on the basis of their achievements in general, and their achievement in a number of school subject areas in relation to estimated ability and to children of the same grade/age, and to estimate educational retardation where it occurred. The teachers reported that, in relation to estimated ability, half (49.5%) of the group were achieving to capacity and nearly a quarter (23.7%) were variable in their school performance, having both strong and weak areas. Nearly a fifth (18.6%) were recorded as under-achieving in relation to capacity.

Figure 6.2: **Distribution of ITPA psycholinguistic age and chronological age for 71 children with spina bifida and hydrocephalus**

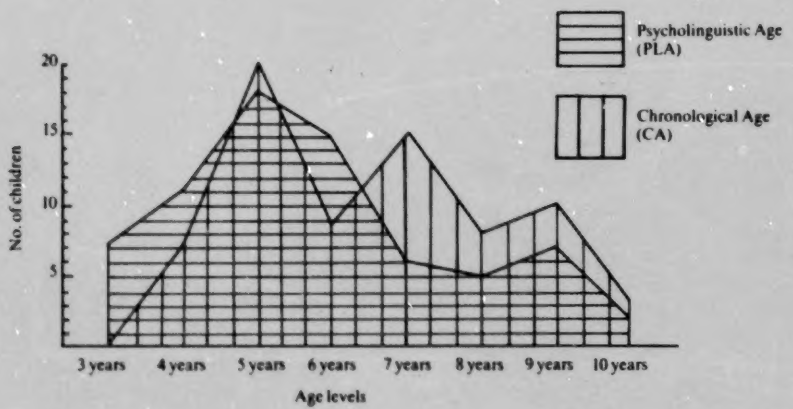


Table 6.33: **Mean academic achievement levels of children: by school placement and school-age level**(*a*)

Test	*Junior primary*		*Middle primary*		*Senior primary*		*Secondary*		*All children*	
	Mean	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school										
Chronological age	6.3	16	8.8	21	11.4	13	12.5	1	8.7	51
Reading										
St. Lucia G.W.R. Test	7.2	3	8.7	19	11.5	13	12.6	1	9.7	36
Woodcock R.M. Test (Pc)	7.7	5	9.0	18	11.7	13	13.3	1	9.9	37
Spelling										
Schonell S. Test (A)	6.5	9	8.5	19	11.5	13	11.0	1	9.0	42
Mathematics										
Moreton M. Tests (II)			8.4	14	8.9	3			8.5	17
Moreton M. Tests (III)					10.6	9	11.7	1	10.7	10
Special school										
Chronological age	6.8	10	9.0	12	11.3	6	13.3	9	9.8	27
Reading										
St. Lucia G.W.R. Test			8.1	4	9.1	6	8.4	8	8.5	18
Woodcock R.M. Test (Pc)			9.7	2	8.9	6	8.2	8	8.6	16
Spelling										
Schonell S. Test (A)			7.7	5	9.3	6	8.4	8	8.5	19
Mathematics										
Moreton M. Tests (II)					7.2	3	7.1	5	7.2	8
Totals										
Chronological age	6.5	26	8.9	33	11.4	19	13.2	10	9.2	78
Reading										
St. Lucia G.W.R. Test	7.2	3	8.6	23	10.7	19	8.8	9	9.3	54
Woodcock R.M. Test (Pc)	7.7	5	9.1	20	10.9	19	8.7	9	9.2	53
Spelling										
Schonell S. Test (A)	6.5	9	8.3	24	10.8	19	8.7	9	8.9	61
Mathematics										
Moreton M. Tests (II)			8.4	14	8.1	6	7.1	5	8.1	25
Moreton M. Tests (III)					10.6	9	11.7	1	10.7	10

(*a*) All achievement scores are in age equivalents.

Table 6.34: **Mean academic achievement levels of children: by school placement and presence of shunt** (*a*)

	No shunt		*Shunt*		*All children*	
Test	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular						
Chronological age	9.2	16	8.3	32	8.6	48
Reading						
St. Lucia G.W.R. Test	10.2	13	9.0	20	9.5	33
Woodcock R.M. Test (Pc)	10.9	13	8.9	21	9.7	34
Spelling						
Schonell S. Test (A)	9.6	14	8.4	25	8.8	39
Mathematics						
Moreton M. Tests (II)	8.7	6	8.5	10	8.6	16
Moreton M. Tests (III)	10.6	4	10.9	4	10.7	8
Special						
Chronological age	11.1	15	8.9	22	9.8	37
Reading						
St. Lucia G.W.R. Test	8.9	11	8.1	7	8.6	18
Woodcock R.M. Test (Pc)	8.8	10	8.4	6	8.6	16
Spelling						
Schonell S. Test (A)	8.7	11	8.2	8	8.5	19
Mathematics						
Moreton M. Tests (II)	7.2	6	7.1	2	7.2	8
Totals						
Chronological age	10.1	31	8.6	54	9.1	85
Reading						
St. Lucia G.W.R. Test	9.6	24	8.7	27	9.2	51
Woodcock R.M. Test (Pc)	10.0	23	8.8	27	9.1	50
Spelling						
Schonell S. Test (A)	9.2	25	8.4	33	8.8	58
Mathematics						
Moreton M. Tests (II)	7.9	12	8.3	12	8.1	24
Moreton M. Tests (III)	10.6	4	10.9	4	10.7	8

(*a*) All achievement scores are in age equivalents.

Table 6.35: **Mean academic achievement levels of children: by school placement and sex**

	Males		*Females*		*All children*	
Test	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school						
Chronological age	8.7	26	8.8	25	8.7	51
Reading						
St. Lucia G.W.R. Test	9.9	17	9.5	19	9.7	36
Woodcock R.M. Test (Pc)	10.4	16	9.5	21	9.9	37
Spelling						
Schonell S. Test (A)	8.9	21	9.2	21	9.0	42
Mathematics						
Moreton M. Tests (II)	8.4	10	8.7	7	8.5	17
Moreton M. Tests (III)	10.4	5	11.0	5	10.7	10
Special school						
Chronological age	9.5	21	10.2	16	9.8	37
Reading						
St. Lucia G.W.R. Test	8.4	8	8.7	10	8.5	18
Woodcock R.M. Test (Pc)	8.8	7	8.6	9	8.6	16
Spelling						
Schonell S. Test (A)	8.4	9	8.6	10	8.5	19
Mathematics						
Moreton M. Tests (II)	7.2	6	7.1	2	7.2	8
Moreton M. Tests (III)						
Totals						
Chronological age	9.1	47	9.3	41	9.2	88
Reading						
St. Lucia G.W.R. Test	9.4	25	9.2	29	9.3	54
Woodcock R.M. Test (Pc)	9.9	23	9.2	30	9.2	53
Spelling						
Schonell S. Test (A)	8.7	30	9.0	31	8.9	61
Mathematics						
Moreton M. Tests (II)	7.9	16	8.4	9	8.1	25
Moreton M. Tests (III)	10.4	5	11.0	5	10.7	10

When these assessments were applied to 5 basic school subjects (Table 6.36), a rather higher than usual percentage of non-response to the item was obtained from the teachers (up to 25 per cent on the spelling rating). Numbers of students ranging from 19 (19.6%) to 27 (27.9%) were said to be not achieving to capacity on reading, spelling, mathematics, handwriting and written expression. When these subjects and oral expression and listening were rated on the basis of comparison with children of the same age/grade (Table 6.37), up to one-half were rated as achieving at below or well below average levels (maths and written expression), with at least 32 per cent similarly rated on all other subjects. The above-average category received relatively few responses (from 3% to 14%). The subjects in which children were seen as performing least well were mathematics, handwriting and written expression.

Of the 41 children indicated to be under-achieving, or showing some variability in results, teachers sought to give reasons for the under-achievement (Table 6.38). In 9 cases they reported the child's handicap was used as an excuse by the child. Also mentioned but in much smaller frequencies were reasons of emotional difficulty and lack of effort, over-protection by parents and teachers' low expectations, and missing earlier groundwork. Frequent absences and insufficient teacher time were only referred to on 2 occasions each. No reason was given in 16 cases.

Table 6.39 estimates the difference in performance effort in a number of subject areas for children with and without shunts in both the regular and special schools. The Chi-square tests indicate no relationship between the teachers' estimates of whether the subjects were working to capacity or not, compared in this way. However, in the Chi-square results for primary and special school children, irrespective of whether the children had a shunt, significant differences did occur in the subject areas of written expression and mathematics.

Table 6.36: **Teachers' assessments of children's achievements in relation to estimated ability: by subject areas**

Assessment	*Reading*		*Spelling*		*Maths*		*Handwriting*		*Written expression*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Is achieving to capacity	69	71.1	50	51.5	62	63.9	67	69.1	46	47.4
Is not achieving to capacity	19	19.6	22	22.7	26	26.8	21	21.6	27	27.9
Missing data	9	9.3	25	25.8	9	9.3	9	9.3	24	24.7
Totals	97	100.0	97	100.0	97	100.0	97	100.0	97	100.0

Table 6.37: **Teachers' assessments of children's achievements compared with other children of same age/grade: by subject areas**

	Reading		*Spelling*		*Maths*		*Writing*		*Written expression*		*Oral expression*		*Listening*	
Assessment	*No.*	%	*No.*	%	*No.*	%	*No.*	%	*No.*	%	*No.*	%	*No.*	%
Well below average	29	29.9	28	28.9	34	35.0	18	18.6	27	27.8	15	15.5	12	12.4
Below average	16	16.5	14	14.4	16	16.5	31	31.9	23	23.7	21	21.6	19	19.6
Average	29	29.9	22	22.7	34	35.1	33	34.0	20	20.6	40	41.2	47	48.4
Above average	14	14.4	9	9.3	3	3.1	6	6.2	5	5.2	12	12.4	11	11.3
Missing data	9	9.3	24	24.7	10	10.3	9	9.3	22	22.7	9	9.3	8	8.3
Totals	97	100.0	97	100.0	97	100.0	97	100.0	97	100.0	97	100.0	97	100.0

Table 6.38: **Reasons for under-achievement**

Reasons given	*No. of children*	*Per cent of group*
Uses handicap as excuse	9	22.0
Given up trying	3	7.3
Emotional problems	3	7.3
Over-protective parents and teachers' low expectations	3	7.3
Poor foundation in basic work	3	7.3
Frequent absences due to handicap	2	4.9
Insufficient teacher time	2	4.9
Missing data	16	39.0
Totals	41	100.0

Estimates by teachers of the children's ability to benefit from extra help in reading and mathematics indicated large proportions, of those for whom data were provided, who could benefit: some 45 per cent in reading and 57 per cent in mathematics. While such comments might be expected among special school students, the judgments of remedial need were almost the same for students in regular placement.

6.3.8 Visual–motor integration skills

The Beery Test of Visual Motor Integration (VMI) (Beery 1967) is a test of complex figure copying, which can be used over a wide age range to assess ability in visual–motor integration. The 95 children tested showed a marked mean deficit of 2 years 8 months. This pattern was evident at all age levels and types of school placement, but was most pronounced among older special school children (Table 6.40). No clear difference was noted among diagnostic categories, each group having similar discrepancies between chronological age and VMI age-equivalent scores. Differences between the performance of boys and girls were also very slight.

6.3.9 Social–emotional characteristics and social aspects

Social–emotional characteristics

As part of the overall review which teachers were asked to undertake of the spina bifida or hydocephalic children in their classrooms, teacher ratings were sought on the children's emotional characteristics in terms of independence, frustration, attention-seeking activities, striving for success and improvement, and initiative shown. Teachers believed that more than half of the group of 116 spina bifida or hydrocephalic children always used the independence skills they had, but that 13.8 per cent rarely or never employed them in their school activities.

Nearly half (46.6%) of the group displayed frustration similar to other children and 13.8 per cent showed less frustration than other children. On the other hand, 30.2 per cent were rated as displaying more. Frustration shown by the disabled children was also analysed by type of school attended and extent of mobility problems experienced (Table 6.41). For children in regular primary and special schools, it will be noted that increased frustration tends to be displayed by children with severe rather than mild mobility problems, and by children in special schools more than those in regular schools.

Table 6.39: **Teachers' assessments of children's achievements in a number of subject areas**

	Written expression		*Handwriting*		*Maths*		*Spelling*		*Reading*	
	To capacity	*Not to capacity*	*To capacity*	*Not to capacity*	*To capacity*	*Not to capacity*	*To capacity*	*Not to capacity*	*To capacity*	*Not to capacity*
Regular school										
No shunt	9	5	13	3	11	5	11	4	11	5
Shunt	21	4	25	6	27	4	17	6	28	3
	($X^2_1 = 1.01$; ns)		($X^2_1 = 0.12$; ns)		($X^2_1 = 1.26$; ns)		($X^2_1 = 0.11$; ns)		($X^2_1 = 2.11$; ns)	
Special school										
No shunt	5	9	11	4	9	6	10	5	13	2
Shunt	9	9	17	7	14	10	10	2	15	9
	($X^2_1 = 0.20$; ns)		($X^2_1 = 0.04$; ns)		($X^2_1 = 0.05$; ns)		($X^2_1 = 0.29$; ns)		($X^2_1 = 1.60$; ns)	
Primary school	30	9	38	9	38	9	28	10	39	8
Special school	14	18	28	11	23	16	20	7	28	11
	($X^2_1 = 6.86$; $<.01$)		($X^2_1 = 0.54$; ns)		($X^2_1 = 3.94$; $<.05$)		($X^2_1 = 0.06$; ns)		($X^2_1 = 0.97$; ns)	

Table 6.40: **Mean visual–motor integration scores of children: by school type and school-age level**

School type	*Pre-school*		*Junior primary*		*Middle primary*		*Senior primary*		*Secondary*		*All children*	
	Mean	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*	*Mean*	*No.*
Regular school												
Chronological age	4.7	5	6.3	16	8.8	21	11.4	13	12.5	1	8.7	56
VMI age	3.9	5	5.6	16	7.1	21	8.6	13	10.9	1	7.1	56
Special school												
Chronological age	5.1	1	6.8	10	9.0	12	11.3	6	13.5	10	9.8	39
VMI age	4.7	1	4.6	10	5.7	12	6.4	6	6.6	10	5.8	39
Totals												
Chronological age	4.8	6	6.5	26	8.9	33	11.3	19	13.4	11	9.0	95
VMI age	4.1	6	5.2	26	6.6	33	7.9	19	7.1	11	6.4	95

Table 6.41. **Frustration shown by subjects, in comparison with others: by type of school and extent of mobility problems(*a*)**

	Severe mobility problems										*Mild mobility problems*											
	More frustration shown		*No difference*		*Less frustration shown*		*No response*		*Totals*		*More frustration shown*		*No difference*		*Less frustration shown*		*No response*		*Totals*		*All subjects*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Regular school	7	18.9 (13.2)	20	54.1 (37.7)	4	10.8 (7.6)	6	16.2 (11.3)	37	100.0	1	6.3 (1.9)	13	81.2 (24.5)	1	6.3 (1.9)	1	6.3 (1.9)	16	100.0	53	100.0 (100.0)
Special school	16	45.7 (40.0)	14	40.0 (35.0)	5	14.3 (12.5)			35	100.0	2	40.0 (5.0)	3	60.0 (7.5)					5	100.0	40	100.0 (100.0)
Totals	23	31.9 (24.7)	34	47.2 (36.6)	9	12.5 (9.7)	6	8.3 (6.4)	72	100.0	3	14.3 (3.2)	16	76.2 (17.2)	1	4.8 (1.1)	1	4.8 (1.1)	21	100.0	93	100.0 (100.0)

(*a*) Percentages are for each type of school and degree of mobility problems, except for those in parentheses, which are for each school type and for the total group.

It was also noted that the children's disabilities were not often used by them to gain attention from teachers or peers, with only 7 per cent and 11 per cent respectively using their disability frequently or sometimes for this purpose.

One of the undesirable effects of disability on these subjects, as reported by teachers, was the tendency not to show initiative. On analysis of this characteristic, by type of school and severity of mobility problems, a quarter of the group of 93 students who were assessed in this area showed initiative on all occasions, approximately 45 per cent displayed initiative sometimes, while the remaining one-quarter of the group rarely or never showed initiative. There is also a trend for lack of initiative to be displayed more by special school students than regular school students and by children with severe mobility problems.

The above observations for display of initiative are supported by those on striving for success for the group of 116 children. Only 35 per cent were reported as always seeking to improve in school-work, while a similar proportion strived to improve sometimes. On the other hand, 18 per cent of the group seemed to rarely or never seek improvement in their school-work.

This area of seeking to improve in school tasks was also analysed by school type and degree of mobility problems, and the previous pattern of findings is confirmed. As for the teacher estimates of the children displaying frustration, this analysis of the initiative shown indicates a trend for less striving for improvement in academic tasks by students in special schools and by children with severe mobility problems.

Social aspects

Some 65 per cent of the children of primary and secondary school age experienced average popularity within their classrooms, with the balance of children, in approximately equal numbers, seen as very popular, or not very popular and socially isolated.

A breakdown of this information by school type (regular and special) and by school age level indicated:

(a) Younger children in regular schools tend to be more popular with their peers than older children.
(b) No child in a regular school was socially isolated.
(c) A greater proportion of special school children were seen by their teachers to be not popular or isolated.
(d) Lack of popularity occurs in both school types at all age levels.

Half of the group of 97 children were known by their teachers to have a special friend and 35 per cent were known not to have such a friend. These proportions are approximately 60 per cent and 40 per cent respectively for those 84 children for whom the information was known. This proportion was consistent over school type and school age level, except that younger children in special schools appear to have fewer special friends.

Teacher estimates indicate that unkindness is occasionally shown at school to some 30 per cent of children with spina bifida and hydrocephalus. No evidence was obtained that this result varies over school types or school age levels. Observations by the child's teacher and reports by other teachers and parents were the main sources of information about unkindness. In only 2 cases (6.9%) did children complain about unkindness and in only 5 cases (17.2%) did other children report unkindness.

The reaction to unkindness by the 29 children was also recorded. Some 40 per cent of the group (12 children) reacted in positive ways, ignoring it cheerfully or coping with the situation; 35 per cent (10 children) reacted with withdrawal or being upset; and one-fifth of the children (6) were angered by unkindness and reacted in verbal (13.8%) or physical (6.9%) ways.

Aggression was more likely to be shown towards classmates (34.0%) than to other children (19.6%), although this result may well be influenced by lack of opportunities for normal interactions with children outside the child's own class group. There was no significant difference in aggression shown towards classmates when analysed by regular and special school and by school age level.

Information on the extent of curiosity shown by classmates in respect of a spina bifida or hydrocephalic child's disability, on the child's reactions to curiosity and on classroom discussions about handicap was provided by 62 teachers in schools other than pre-schools and schools for the physically handicapped. No curiosity was shown by classmates in 60 per cent of these classrooms, with a little and much curiosity being shown towards 27 per cent and 5 per cent respectively of the children involved. Some 8 per cent of the teachers reported they were unaware of any curiosity being shown.

The 20 children who were the subject of curiosity were also observed in respect of their reactions. Some two-thirds ignored the experiences cheerfully and only 3 children (15%) were reported to withdraw or be upset by the experience. The teachers' reports also indicated that in 37 of the 62 classrooms (59.7%) no discussion about handicaps had taken place. About equal proportions of teachers in primary and secondary schools (35%) had had such discussions. All special school teachers involved reported discussions in class on this topic.

Use of the playground

A further aspect of social relationships explored with the teachers was the use of the school playground by the group of spina bifida/hydrocephalic children. Some 86 per cent of the group, excluding pre-school children, used the school playground, while 14 per cent did not. No differences in the use of the playground by children in regular and special schools, or of different school age levels, were observed. Table 6.42 further reveals that, in addition to those students who did not use the playground, 13 per cent were never involved in group play. Those children who were involved were included at variable frequency levels, with only 12 per cent of the disabled children always included with their peers. Of the 13 students who used the playground, but were never involved in group play, 8 engaged in play activities with 1 or 2 others, while 3 did not play at all and 2 played alone. It was noted that 59 per cent of the disabled children were always included in play without teacher direction.

Table 6.42: **Extent of involvement in group play in playground**

Extent of involvement	*No. of children*	*Per cent of group*
Involved in group play		
Always	12	12.4
Often	20	20.6
Sometimes	37	38.1
Never involved in group play	13	13.4
No use of playground	14	14.4
Missing data	1	1.1
Totals	97	100.0

6.3.10 Teaching approaches

Class organisation

Regular primary school class organisation in Queensland appears to be predominantly based on heterogeneous groups, as only 4 children of those in 49 regular primary schools in this study were in classes streamed on an ability basis within the grade level. Of these, 1 child was placed in the upper stream and 3 were in the lower stream class. The average size of primary school classes was 29.8 children (see Table 6.2). The majority of the group (81%) were placed appropriately for their age but a number were retarded by 1 or more years.

It was a frequent practice among the regular primary school teachers to provide for differing ability levels within their classes. Ninety-two per cent of teachers reported they followed this practice for reading and 86 per cent did so in mathematics. In both cases there was a trend towards lower group membership for the target group of children, especially in reading.

Approximately 22 per cent of the teachers reported working co-operatively with other teachers to instruct their classes in reading and/or mathematics. Of the 22 per cent of children taught under this approach, few were placed in the upper groups.

Special school class organisation is not typically based on the same principles as those employed in regular schools. However, within these classes, 82 per cent of the spina bifida and hydrocephalic children were undertaking work in reading and mathematics in a small group. In both these subject areas, only 5 students (12.5%) worked individually. Since teaching employing within-class groups was the dominant approach in the special schools, an estimate was made by teachers of the children's ability to work co-operatively in these settings. Table 6.43 indicates that a small proportion of these children found co-operative working was not possible, but 35 per cent were able to handle the approach. A similar pattern was found for reading and mathematics.

Table 6.43: **Ability to work co-operatively with others: special school children working in groups**

	Reading		*Mathematics*	
Level of co-operation	*No.*	%	*No.*	%
Can work co-operatively	14	35.0	14	35.0
Needs some individual attention	7	17.5	11	27.5
Needs much individual attention	7	17.5	5	12.5
Cannot work co-operatively	5	12.5	3	7.5
Missing data	7	17.5	7	17.5
Totals	40	100.0	40	100.0

Need for extra teaching assistance

The need for assistance in reading and mathematics was explored for the total group of 97 students — that is, excluding the pre-school children. Nearly half of this group (48.5%) were judged not to need special assistance with reading and 36 per cent did not need assistance with mathematics. However, of those students for whom the information was provided, 45 per cent needed help with reading and 57 per cent needed help with maths, but in reading, this assistance was not available to one-third of these children and in mathematics, was not available to nearly half.

Among personnel providing assistance, remedial/resource teachers assist more frequently in reading (34%). Class teachers appeared to meet a substantial part of the need in both reading (21%) and mathematics (31%), followed by teacher aides (almost 20% each subject). Parents also filled a useful role in these activities. Special assistance was given to some 40 per cent of the group at a frequency of from two to four times weekly in both subject areas, and daily to approximately 35 per cent. A significant group received assistance only on an occasional basis.

Class grouping and the target children

In the formation of groups for various school activities the spina bifida/hydrocephalic children need to be allocated by the teacher, or selected by their peers if that approach is followed. Of the 97 teachers surveyed, 74.2 per cent stated that they predominantly employed a group organisation for class activities. This procedure was consistent over types of school (regular and special) and school age levels.

Of the 97 teachers, 44.3 per cent followed the procedure of allocating children to groups themselves, when grouping was employed, and an equal number reported that groups were formed by the children choosing group membership. Of the cases where children chose group membership, 70 per cent of the spina bifida/hydrocephalic students were chosen on the average as frequently as other children and only a slight trend is evident toward them being chosen less frequently or hardly ever (Table 6.44). Again this result was consistent over regular and special schools and by school age level. Of those children chosen less frequently or hardly ever, teachers judged unacceptable behaviour to be a dominant reason.

Table 6.44: **Selection of spina bifida child by others in class grouping**

Selection frequency	*No. of children*	*Per cent of total group*	*Per cent of valid cases*
Child chosen very frequently	4	4.1	9.3
Child chosen average number of times	30	30.9	69.8
Child chosen less frequently than most	6	6.2	13.9
Child hardly ever chosen	3	3.1	7.0
Groups not selected by children	43	44.3	–
No response	11	11.4	–
Totals	97	100.0	100.0

Approximately half the teachers reported giving the disabled children special consideration when forming class groups. Also, 42 per cent of those teachers who reported that class duties were allocated among the class members did not allocate a duty to the disabled child.

Exclusion and allowances related to school activities

Nearly 80 per cent of the 97 subjects were not excluded from any aspects of the curriculum on account of their handicap. In those cases where exclusion occurred, academic areas were not involved and exclusion was related to physical education and similar activities. It might be assumed in discussing this topic that the curriculum and practices in special schools are modified to suit children as a matter of course, and this would be reflected in the data.

After excluding children at schools for the physically handicapped, teachers were also asked what allowances they made, because of the child's physical handicap, to compensate for the effects of the disabling condition. Almost half reported making no such allowances, but one-third gave extra time for tests or excused poor handwriting and 11 per cent gave extra encouragement.

The same teachers were also asked to indicate what extra help they provided in daily class-work. Sixty per cent of the students received no extra assistance, while 18 per cent were given increased individual attention by the teacher. Preparation of special work-sheets, acceptance of oral rather than written answers, and allowance of extra time are practices which are not widely followed to assist the children in daily class-work.

It was the practice of 36 teachers out of the 97 reporting not to prescribe homework. Of those children who received homework, nearly 68 per cent completed it adequately, with 30 per cent doing a less adequate job. More than half (62.3%) of the children who were given homework were assisted with it by their parents, 27.6 per cent of parents were said not to assist and the teachers were unaware of the situation in a further 13.2 per cent of cases.

6.3.11 Class management

The management of a class group in which a disabled child is enrolled may involve instances of maladaptive behaviour by the child, extra demands on the teacher's time, and problems in locating the child within the classroom. Together, these aspects comprised 80 per cent of the problems said by teachers to occur as a result of a spina bifida/hydrocephalic child enrolled in a class group. The 116 teachers surveyed were requested to indicate the extent of maladaptive behaviour in these students and the effects it had on both the child's learning and the class generally. Maladaptive behaviour was reported in 20 (17.2%) cases. Of these, the teachers judged that this behaviour interfered with the child's learning in 18 cases (severely in 6 cases) and disturbed the class in 17 instances. In most cases of class disturbance, however, this was reported to have a minor effect.

Few teachers (4.3%) found that the disabled child created consistently heavy demands on their time and nearly 70 per cent reported that no extra demands of this type were made. In only 26 of the 116 cases (22.4%) were moderate levels of demand on the teacher's time reported.

The effects of spina bifida on mobility was the major reason for needing to consider a special position for a disabled child within classrooms. This was reported in nearly 40 per cent (38) of cases for children in regular and special schools (excluding pre-schools). Poor vision was an important consideration in 9 children; poor hearing, in 2 students. These latter situations would occur almost as frequently among the regular school population.

6.3.12 Information available to teachers

Details of the information on spina bifida that is available to school principals was reported earlier in this chapter, together with discussion on the sources of the information.

Classroom teachers, except teachers of the children enrolled in pre-schools and schools for the physically handicapped, reported on their prior knowledge that the disabled child would be in their class, their knowledge of spina bifida/hydrocephalus, and other past experiences which were likely to prepare them for the task of teaching a disabled child. Nearly 70 per cent (48) of these 70 teachers knew in advance that the child would be in their class group. About half the teachers received children who moved up from lower classes, a quarter were advised by the school principal and 6 per cent were approached directly by parents.

Of the 48 teachers who knew that a handicapped child would be one of their pupils, 45 knew the nature of the handicap but only 25 reported that they fully understood the implications of it. It should be noted, however, that of these teachers, at least one-quarter did not have prior knowledge of the enrolment and approximately the same proportion had no understanding of the implications of the condition.

However, nearly half of these 70 teachers (47.1%) indicated that they experienced no concern about the child's enrolment during the early part of the school year, while 43 per cent reported some degree of concern. At the same time, 54 per cent had had previous contact with persons with physical handicap; 37 per cent had not.

A group of 97 teachers (excluding the pre-school teachers) provided details of information received and discussion opportunities they had had about spina bifida. While 65 per cent had received information without having to seek it, 12 per cent had received it when it was sought and 15 per cent of teachers had not received any information. There was no consistent source of this information. By far the majority of teachers received it from multiple sources, with parents, medical personnel, guidance officers and colleagues all assisting. Opportunity for discussion about the child and the condition with guidance officers or visiting teachers was limited, with 41 per cent reporting discussions available less than once a term and 38 per cent never having the opportunity. Few teachers (6.2%) were able to hold these discussions more than once a term.

Only 57 of the total group of 116 teachers (49.1%) reported that their training course dealt with special education subjects, including physical handicaps. On the other hand, most regular school teachers appear to have adjusted well to the presence of a spina bifida child in their classroom. No present concern at this situation was being experienced by 86 per cent of the group, with 8 per cent of teachers expressing some degree of concern.

Contact with parents

Contact with the parents of their disabled students had occurred for 75 per cent of all teachers. Of the 90 teachers who had had contact with parents or other relatives, almost all had done so on 2 or more occasions.

6.3.13 School placement

The final aspect reported in this section concerns the teachers' judgments about the school placement of the disabled child. Of the teachers in regular and special schools (excluding pre-schools), 83 per cent considered the present school placement to be the most suitable; 13 per cent considered it was not, and 3 teachers did not express a view. The 13 teachers who judged that the present placement of the child was not the most suitable represented 10.9 per cent of all regular school teachers and 17.9 per cent of special school teachers — that is, slightly weighted towards special school teachers showing more dissatisfaction with present placement of the children.

Of the 13 children judged to need different placements, the 6 students in regular schools were seen by their teachers to require smaller classes within regular schools. The teachers of the children enrolled in special schools generally suggested they would be more appropriately placed in a different special school, while 2 children were seen to need placement associated with the vocational or residential needs of the student. That is, a 15-year-old student at a special school for the physically handicapped was seen to need sheltered-workshop placement or a school with pre-vocational training provision, and the other student, also at a school for physically handicapped, was seen to need placement in a school for mentally handicapped children with cottage-type residential facilities (this placement has since been made).

Teachers in regular primary schools and in special schools were requested to predict the future success of a placement of their students in regular secondary school. Overall, 40 per cent of the children were expected to cope, the teachers were uncertain in 23 per cent of cases and there was a clear prediction that 34 per cent of the students could not be expected to manage regular secondary schooling. This information was further analysed by regular primary and special schools and it was observed that the pattern of prediction varied significantly. In regular primary schools, most teachers (55%) felt able to predict that their students would manage, but only 24 per cent of special school teachers made this prediction.

On the other hand, 63 per cent of special school teachers predicted their students could not cope with regular secondary schooling, against 13 per cent of regular primary school teachers. However, regular school teachers recorded uncertainty about more students than did special class teachers.

6.3.14 Summary

This section, reporting data provided by 116 classroom teachers of children experiencing spina bifida and hydrocephalus, is a detailed overview of information on the school experiences of the children, the characteristics of the students, and the practices and judgments of the teachers. The significant roles played by both teachers and parents in maintaining the children in regular schools is highlighted. Details of the extent of need for modifications of furniture and buildings to better cater for severely physically handicapped children are given, but were not found to be a major concern.

Most teachers made some adjustments to their teaching strategies when necessary to meet the pupil's needs and generally were found to be very receptive and supportive of them. The effects of disability were identified within a wide range of aspects of school life, with some variation being found as a result of the type of school which a child attended (regular or special) and the severity of the child's problems resulting from the disability.

A review of the results on the WISC, WPPSI and IPTA for these children does not reveal any strong trends to support some of the published research findings reported in Chapter 2. Mean scores on the WISC and WPPSI Vocabulary subtests were high, as was the mean score on the Similarities subtest on the WPPSI. On the WISC, the mean Coding score was low. Subtest scores on the ITPA likewise did not show any significant patterns, especially in support of the notion of a high level of verbal skills in spina bifida and hydrocephalic children. While the overall trend of results indicated somewhat higher verbal than performance skills, marked discrepancy between these areas was not present. However, the general intellectual levels are consistent with those reported in the literature.

Analysis of results on academic achievement tests indicate similar results tó those previously reported, especially lower scores for children enrolled in special schools. Generally the school performance of these children in academic areas was consistent with their chronological age in the case of those in regular schools, and their intellectual levels, in the case of those attending special schools, as would be expected.

The section also describes the social and emotional characteristics and experiences of the subjects, and finally, the relevance of the children's current school placements and a future education prognosis.

6.4 Physical and social interactions

To provide extra information, a detailed, diary-style, 1-day observation study was undertaken of a number of the spina bifida children enrolled in primary schools in the metropolitan area and 2 nearby provincial cities. A group of 30 children (17 boys, 13 girls) was identified, enrolled in an equal number of schools. The parents of 2 subjects (both boys) withheld permission for the observation and the number of children included was therefore reduced to twenty-eight. This was an otherwise unselected group of children with spina bifida, and it was planned that the observation period would provide data that represented a typical situation for these children in regular schools but which could not be provided by questionnaire or testing procedures. The observation day was randomly selected over a 2-week period in mid-year.

The reports of the observers provided an indication of how children with spina bifida present in a regular classroom setting. Their records indicated that, of the 28 children studied:

(a) Only 6 (21.4%) presented as having significantly different personal appearance beyond the effects and/or implications of their spina bifida. These children were noted to have turned feet (3), a slightly abnormal head, to be the only child in the class with long trousers, and wearing shoes on the opposite feet.

(b) Twenty-five (89.3%) of the 28 children had visible aids and appliances. Those reported were a urinary bag (18), orthopaedic shoes (14), 2 calipers (11), crutches (11), wheelchair (4), single caliper (2), a special desk (3) and 1 case each of a special chair, diaper bucket in the classroom, row car and parapodium.

(c) Twenty-six (92.9%) children had an abnormal gait, most (16) being judged to be moderately abnormal. Five were reported to have a slight limp, 4 could walk without crutches and 1 was very limited in walking with aids.

(d) Twenty (71.4%) had impaired ability to negotiate stairs. Of these, most were independent though slow, but 2 children needed peer assistance and 3 negotiated stairs on their bottoms with 1 also carrying his mobility aids.

(e) Nine (32.1%) children had significantly different methods of travel to and from school, compared with other children. Of these, 2 travelled by taxi with assistance, 2 needed assistance to use a private car and 2 were carried into school. One child travelled by special bus, 1 by taxi (unassisted) and 1 left early to catch a bus service.

(f) Twelve (42.9%) children had impaired fine motor co-ordination. Of these, 10 were reported to have slight difficulty and 2, considerable difficulty.

(g) Fifteen (64.3%) had different toileting arrangements. Seven of these children were toileted in school class time, 3 were assisted by peers and 3 were assisted by parents during lunch break, 2 toileted while the class ate lunch, 2 were noted to have a collection appliance and 1 had extra pants at school.

(h) Thirteen (46.6%) of the 28 children had difficulties with classroom seating or positioning. Two could not sit on the floor, 4 experienced discomfort when on the floor for class activities, 3 had difficulty standing for activities, 3 sat in isolated desks and 1 experienced discomfort at a standard school desk.

The observation study also included an analysis of the physical and social interactions involving the group of 28 primary school children during a typical school day. It sought to make a detailed record of all physical movement within and outside the classroom and of participation in group activities at school assembly, during lunch periods and in the playground and physical education lessons.

It was observed that:

(a) Seventeen (60.7%) of the 28 children experienced limitations of movement within their classrooms. In 4 cases, movement was considerably impeded by inappropriate classroom furniture. Of the 17 students, 7 were able to move unassisted in limited areas; 4 were able to move only, or largely, with assistance; 3 moved with occasional assistance; and 3 children at times moved on their bottoms.

(b) Eleven (39.3%) had special arrangements for movement between classrooms and teaching areas. Four of these needed assistance and 7 moved at special times, either before or after the class group.

(c) Eight (28.6%) students entered their classrooms at special times, half of them being especially placed to facilitate this movement, while the remaining 20 students achieved normal class entry.

(d) In 14 schools, no formal school assembly was held on the observation day. In the other 14 schools, in which an assembly was held, only 2 (7.1%) children remained in their classrooms during this time, the others joining their classmates in the school assembly.

(e) Thirteen (46.4%) of the 28 children had special lunch arrangements, while 14 took lunch along with their peers and 1 student went home for lunch. Of the 13 students, 5 had their lunch bought from the school canteen by peers, 4 had difficulty eating, 1 ate lunch in the classroom with friends, 1 sat on the floor to be able to get his lunch from a bag and 1 did not eat lunch.

(f) Twenty-one (75%) students had different routines during time usually spent in the playground. Of these, 10 were left out of activities and were alone for considerable periods of time, 4 were wheeled around by peers in turn and 2 stayed in the eating area during playtime. One student had piano lessons and practice, another spent the time with younger children, while another stayed in class with a classmate chosen by the teacher.

(g) Fifteen (53.6%) of the students did not participate or had difficulty participating in physical education periods. Of these, 6 attended the lesson but were exempted from participation, 6 were not able to be fully involved in the lesson, 2 engaged in activities adopted by peers, and 1 child stayed in the classroom.

In general the mobility problems of spina bifida children were seen to exert a significant influence on their school experiences in the social and personal relationships area more than in relation to academic activities. Assistance is given quite freely by peers and teachers to enable essential movement around the school, and in some cases by peers in recreation or play. A major consideration arising from this aspect of the research was concerned with the progression by a physically handicapped child from a wheelchair to crutches, seen as a progressive step in the development of mobility skills. Many children and adolescents develop great skill in the use of a wheelchair, but a wheelchair also tends to engender considerable social sympathy and attention. Clearly some of the children found that when crutches were employed for mobility around the school and in the playground, social contacts tended to decrease and some sought to retain the use of a wheelchair. This point is related to the information presented previously in Table 6.16. It was noted that, in all, 43 per cent of this group of 116 students used wheelchairs. Table 6.17 also records the extent of use of wheelchairs by these subjects. Only 15 per cent used them all of the time.

A sociometric study

At an early stage during the assessment and observation of a group of the target children in primary schools in the metropolitan area and 2 provincial cities, a basic set of sociometric data was obtained for the classes in which 29 children were enrolled. Twelve of these children were in the junior grades (1 and 2), 11 were in middle primary school grades (3–5) and 6 were in the 2 senior grades. Sixteen were boys and 13 were girls.

The procedure followed was to request each child to list in order of preference the 3 other children in the class with whom they would like to work and, if they wanted, to name a child with whom they would not like to work. The sociometric status (Gronlund 1959) was calculated for all pupils. Twenty-two of the 29 children with spina bifida/hydrocephalus were located below the mean sociometric status for their class groups. Only 7 had scores above the class means. In status terms, 8 children were below average and bordering on rejection, while 2 were outright rejects; 7 children were neglectees and 1 was an isolate.

The results for the children in the 29 classes are presented in Figure 6.3, where a frequency distribution of the scores of 29 spina bifida children is depicted in comparison with the 884 children in their class groups. It will be noted that while the peer group generally portrays a 'normal' distribution in sociometric status, with the mean score located above 0, the distribution of scores for the target group was located at a lower level and was negatively skewed.

Figures 6.4 and 6.5 depict a comparison of the number of choices and rejections received by the disabled children and their classmates.

Of the 913 children in the 29 classrooms for which data were collected, the average number of choices received was 2.8, with a range of 0–13. The average for the spina bifida children was 1.48, with the maximum number of choices being five. The average number of rejections received by each of the children in this population was 0.7 and for the target group, 1.21, with a maximum number of rejections by any 1 child being 12.

Generally, the spina bifida children were less chosen than their peers and slightly more rejected. While none of the spina bifida children was the most chosen in any class group, several were the most rejected in the class. Seven (24.1%) spina bifida children received an above-average number of choices for the total group, while 14 (48.3%) were more rejected than average.

Figure 6.3: **Histogram of total sociometric scores**

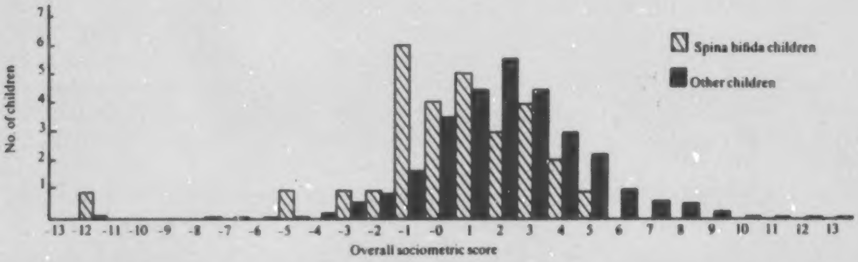


Figure 6.4: **Choices received: sociometric data**

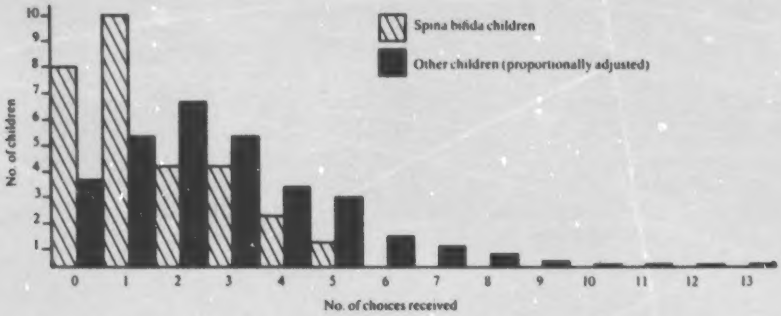
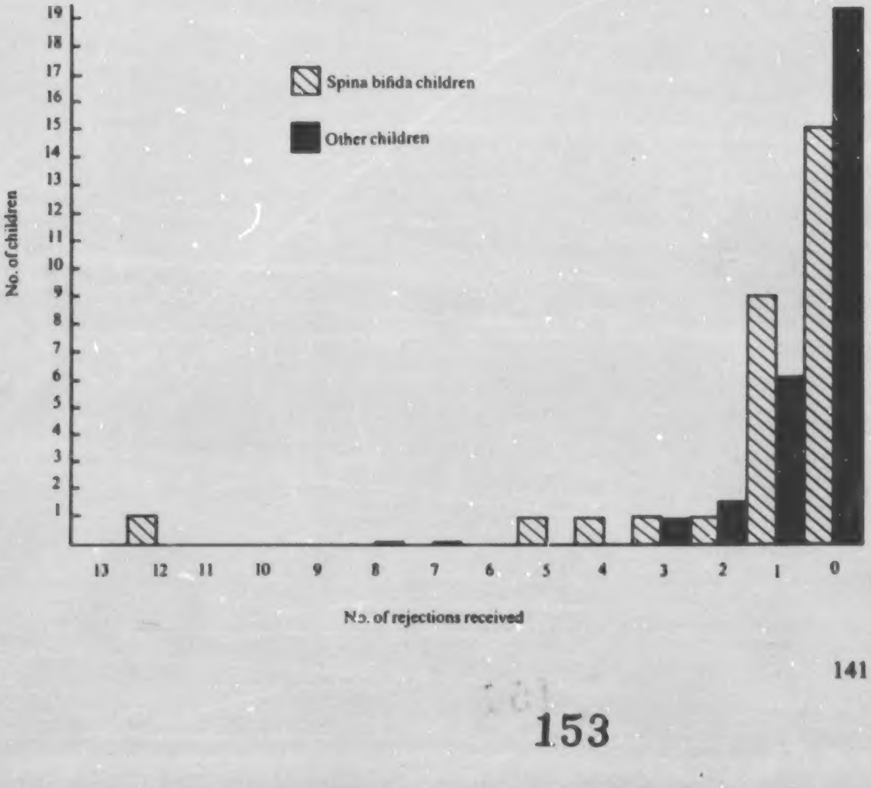


Figure 6.5: **Rejections received: sociometric data**



6.5 SUMMARY

This summary does not attempt to compress into a few pages the detailed results reported in the body of the chapter. Rather it gives a number of observations from the findings. School principals are in a key position in respect of the acceptance and admission of a severely handicapped child into a regular school, the organisation of the school to cater for the child's difficulties with movement and toileting, and the sensitisation of the school community to the needs of such children. School principals were generally supportive of integration but wished to judge its appropriateness for each individual child.

Teachers likewise play a significant role in maintaining severely handicapped children in schools: not only is it often necessary to make modifications to their teaching approaches, it is also frequently necessary to contribute to the child's personal care and movement around the school.

There are important implications for teaching in the characteristics of the spina bifida and hydrocephalic children. These include their mobility and manipulative skills and their socio-emotional and cognitive characteristics.

As with cerebral-palsied children and adolescents, the distribution of intelligence test scores reported in this chapter for spina bifida and hydrocephalic subjects shows a general depression of levels of intelligence and a significant number with scores below I.Q. 85. Unlike cerebral-palsied subjects, there is a rapid falling away of scores at the upper end of this I.Q. distribution. In this research group it will have been noted that 50 per cent of subjects are above and below –1 SD (I.Q. 85). Distributions of cerebral-palsied subjects tend to show one-third of subjects above I.Q. 85. However, these results for spina bifida and hydrocephalic subjects would be influenced by a lower survival rate than for cerebral-palsied subjects.

The levels of intelligence and the distribution characteristics reported for the subjects in this chapter support previous research findings. While many children and adolescents with spina bifida and hydrocephalus perform satisfactorily in regular school programs, some require special educational assistance both within regular schools or special schools. It has been shown that 40 per cent of this group have at least mild levels of mental retardation, and appropriate educational planning and assistance is required for them, regardless of their educational setting. This would include assistance not only appropriate to the intellectual capacity of the children but also in recognition of the specific skill deficiencies which may be identified in the patterns of their individual test scores.

The trend towards placement of these children and adolescents in regular schools is supported by this research. But it is necessary for continued attention to be given to the range of disabilities experienced by them, the need for comprehensive support programs for the children and teachers, and the desirability of making placement in regular schools less dependent on the initiative and effort of parents.

CHAPTER 7

A PILOT STUDY OF FINE MOTOR FUNCTION OF THE UPPER LIMBS IN CHILDREN WITH SPINA BIFIDA

(Denise C. Elkins)

7.1 INTRODUCTION

The study was designed to serve as a pilot investigation which could provide information for a more extensive investigation of fine motor co-ordination in the upper limbs of children with spina bifida. A primary aim of the study was to examine the suitability of various standardised tests and informal assessment procedures for use in future investigations. A second purpose was to obtain evidence concerning the presence of perceptual and motor difficulties in the sample of children and to specify more clearly the nature of such difficulties.

7.2 THE STUDY

7.2.1 Subjects

The subjects in the present study were selected on the pragmatic criterion of availability, and were children attending 2 schools for physically handicapped children in Brisbane. All 17 children diagnosed as having spina bifida and attending the primary school section were selected. The sample of 17 children was supplemented by 2 others: 1 was a pre-school child attending one of the schools for physically handicapped children and the other was a Grade 2 child with spina bifida who attended a regular primary school. No claim of representativeness is made for the sample, and caution must be observed in any attempt to generalise beyond it. However, the sample is probably typical of spina bifida children not placed in regular schools, i.e. those with more severe handicaps.

There were 12 boys and 7 girls, their ages ranging from 4 years 9 months to 14 years 9 months , with a mean age of 9 years 1 month.

Intelligence quotient test results were available for 14 children. The range of I.Q. was from 54 to 104, and the 1 child from a regular primary school was judged by teachers to be at least average in general ability. In summary, the sample was of below average ability, with some children mildly mentally retarded and some within the average range. The mean I.Q. of the 14 children was 77. By searching school records it was determined that 18 children had hydrocephalus. No data were available for 1 child.

All children attending the schools for physically handicapped children used wheelchairs or had full-length calipers. One boy used a parapodium, and the girl attending regular school had short calipers and could negotiate stairs.

7.2.2 Tests employed

The tests were designed to sample gross and fine abilities with the upper limbs at reflex and higher levels.

Defence movement

This test was carried out with the child sitting in a chair or wheelchair. A large (60 cm) inflated ball was thrown 3 times from a distance of 1 metre. The child was asked to catch it or push it away, preventing it from touching the body.

Support

The child was required to lie in the prone position, with the trunk raised and supported on the forearms, and to maintain the position for 10 seconds.

Power hold (screw)

Two plastic nut-and-bolt screw toys were used, 1 large and 1 small. The total time taken to complete both tasks was measured with a stop-watch. Limited normative data was obtained by testing 10 children from a primary school age levels 5, 7, 9 and 11 years.

Tactile tests

Tactile discrimination A screen was used to obscure the child's view of his hands. The operator lightly touched 1 of the child's hands and he was asked, 'Where did I touch you?'. The child would then touch the spot with his other hand.

Shape With the child's hands behind the screen, a shape was outlined on the palm with a fine object. The shapes used were a square, a triangle and a circle. The child was asked what shape had been drawn. If the child was not familiar with the shape names, he could point them out from examples drawn on a card.

Simple objects Two sets of objects — button, ring, coin — were used, 1 set being in view of the child. One object was placed in the palm of the child's hand which was obscured behind the screen. He was then asked to point out the matching object. Both hands were tested.

Proprioception

Finger positioning With the child's hands behind the screen, the child's fingers were positioned by the operator, the positions used being (a) opposition of the thumb and middle finger, (b) flexion of the middle ring and little fingers with the index finger and the thumb extended, (c) flexion of the index finger onto the palm and (d) touching the tips of the index and little fingers with mid-flexion at the metacarpo-phalangeal joints. The child was asked to copy each of these positions with the opposite hand. Each hand was used as the demonstration hand twice.

Postural hold The child was blindfolded in the sitting position. His arms were raised by the operator to shoulder level and he was asked to hold them still. Any tendency for the arms to sink or lift was noted, as were finger movements that the child might use to gain position clues.

Elbow jerk

A toy rubber tomahawk was used to tap the biceps tendon at the elbow joint to elicit a simple stretch reflex.

Vestibular

The child was lifted from behind in the vertical position with his eyes blindfolded and his arms relaxed. The operator then tipped him to an angle of about 35° forward, backward and to either side, righting response and any reaction from the arm.

The Test of Hand Function in Children (Taylor, Sand & Jebsen 1973) was developed from an earlier instrument which was used in rehabilitation settings with adults (Jebsen, Taylor, Treischmann, Trotter & Howard 1969). The 6 subtests (referred to as the Taylor Tests) were:

(a) turning over (76 x 127 mm) cards
(b) picking up small objects and placing them in container
(c) stacking checkers
(d) simulated eating
(e) moving empty large cans
(f) moving heavy large cans

A 7th subtest, writing, was not included because the authors considered it unsuitable for children less than 8 years old. Also, the test used all capital letters, which was considered to be at variance with school practice. Another disadvantage was that cursive writing (not printing) was required. Normative performance is tabulated from 6 to 19 years, but these norms use only 5 age groups, each of width from 2 to 5 years. These norms were judged to be very deficient, as no standard score tables are included and the clinician must judge each raw score in relation to means and standard deviations for the broad age groups. Detailed descriptions of the test procedures are given in Jebsen et al. (1969) and care was taken to reproduce test materials, though some difficulties occurred because of metric conversion in Australia.

The Southern California Motor Accuracy Test (Ayres 1964) is a test which requires the child to trace a butterfly shape with each hand separately. Performance is measured by determining the distances by which the line drawn by the child deviates from the target line at 4 levels of accuracy (in terms of deviation from the target lines). Scores for accuracy are obtained by subtraction of error points from 500. Adjusted scores are obtained by subtracting a weighted time (No. of seconds/10).

Norms are provided for ages 4 years 0 months to 7 years 11 months, which limits the usefulness of the Motor Accuracy Test.

The Southern California Figure–Ground Visual Perception Test (SCFGT) (Ayres 1966b) requires the selection of a figure (common objects and geometric designs) from a background. It is claimed (see Test Manual, p. 1) that the SCFGT is useful in the determination of deficits in visual perception. Liberal time limits of 30 seconds per item mean that speed does not unduly affect performance. Norms are available only for ages 4 years 0 months to 10 years 11 months.

The Copying a Sentence Test (Daniels & Diack 1958) requires the child to copy the sentence, 'The dog sits in his box'. No objective criteria are given for evaluating performance, but Anderson (1976b) timed the performance and used comparative judgment with matched controls.

7.2.3 Design and analysis

Several problems combined to prevent a simple analysis of group mean scores on the various tests and thus enable a composite picture of the sample of spina bifida children to be given. These problems were:

(a) The children were of a very wide chronological age range.
(b) The children were of a fairly wide I.Q. range, and were also of less than average I.Q.
(c) Several tests used were not standardised or had norm tables for only some of the ages of the children in the sample.

It was therefore necessary to use two main forms of analysis. First, each child's pattern of performance on the set of tests was examined with reference to whatever normative data were available in order to arrive at a judgment about competence in fine motor co-ordination, taking into account, somewhat subjectively, both age and intelligence. Second, correlations among several tests were obtained to gauge the extent to which the tests were measuring related aspects of performance.

A further important feature of the analysis was the identification of problems and limitations in the assessment procedures and tests used, in order to guide future research.

7.2.4 Procedure

The children were assessed at school in a vacant room. Usually the testing was spread over 2 sessions of about 30 minutes each. All children appeared to enjoy the testing, except for 1 girl who insisted that she could not do the Southern California Motor Accuracy Test with her left hand. Although some care was taken to ensure a complete data collection, absence, illness, and school visits combined to prevent this goal being achieved. Nevertheless, there were few tests on which the data were incomplete.

7.3 RESULTS

Means and standard deviations for the tests are presented in Table 7.1.

Table 7.1: **Means and standard deviations of the variables** (*a*)

Test	*Mean*	*SD*
Age	9 yrs 1 mo.	38 mos
I.Q.	76.62	16.95
Tactile/shape	3.26	1.15
Tactile/object	2.84	0.37
Finger position	3.05	1.08
Screw	52.06	21.98
SC figure ground	14.83	5.40
Handwriting	66.32	42.17

	Left hand		*Right hand*	
	Mean	*SD*	*Mean*	*SD*
Taylor 1 (Common objects)	11.09	4.29	9.50	2.61
Taylor 2 (Card turning)	11.05	8.09	8.94	4.54
Taylor 3 (Checkers)	9.55	3.53	8.49	2.85
Taylor 4 (Feeding)	19.10	6.74	17.47	6.11
Taylor 5 (Light objects)	11.06	4.23	9.17	3.51
Taylor 6 (Heavy objects)	10.94	5.07	9.28	3.56
SC motor accuracy (time)	97.85	63.18	127.94	75.32
SC motor accuracy (accuracy)	434.29	31.34	447.47	23.53
SC motor accuracy (adjusted)	424.94	28.67	435.65	19.87

(*a*) Where tests were made using each hand separately, analysis has been confined to left or right hand only, rather than dominant and non-dominant. No detailed analysis of degree of dominance was made.

Defence movement

No children showed absence of a defence movement when thrown a large ball. Fifteen children were able to catch the ball, the 4 unable to catch being younger (aged 5–7 years).

Gross support

Because test conditions were unsuitable and the children were wearing calipers, the investigator consulted with the child's physiotherapist in some cases to confirm that the child could do this. In other cases the child was using crutches with a swing-through or alternate gait and their ability to perform this test was assumed.

Vestibular

All the children performed adequately in this test, apart from 1 child who was too heavy to lift.

Tactile

Shape Twelve children performed all 4 tasks successfully and only 1 child failed all four. The mean score was 3.26.

Touch Nine children showed accurate performance in locating the stimulus position. Five children were accurate but slow to respond, and appeared to use tactile clues, touching the wrong point first and gradually moving to the correct point. Two children were slow to respond and inaccurate. Three children responded immediately but were inaccurate.

Similar objects Seventeen of the children performed all 3 tasks successfully. Two children made 1 error. The mean score was 2.84.

Proprioception

Finger positioning The mean score was 3.05 tasks correct, with 11 children scoring the maximum possible of four. However, 7 children scored only 2 and 1 scored only 1 item correct.

Postural hold All children performed this test reasonably well but some showed asymmetry in their holding pattern, 1 arm rising slightly and the other sinking slightly.

Elbow jerk

While this reflex was clearly present in 9 children, it was difficult to elicit the response in the remainder. The investigator formed the impression that some of these children were hypotonic.

Power hold (screw)

The mean time taken for the screwing task was 52.1 seconds. It was expected that performance on this task would be related to age so the mean performance of 10 primary school children at each of 4 age levels was plotted in Figure 7.1. Approximate levels of performance were also established at 1 and 2 standard deviations (SD) above and below the mean. The performance of the 19 spina bifida children was plotted and 10 of these were observed to perform at a level below 2 SD below the mean.

Taylor Tests (hand function)

Since the Taylor Tests have only limited normative information, a similar procedure to that used in the power hold (screw) was selected to represent performance in all 6 parts of the Taylor battery. Also, as performance for left and right hands were highly correlated (Table 7.1), graphs were drawn for the right hand only (Figures 7.2–7.7). It must be noted that most of the spina bifida children were within normal limits on the Card Turning test, with only 5 children performing below the 2 SD mark. Performance on the manipulation of Light Objects was a little worse, with 7 children being markedly slow. On the remaining 4 subtests, the majority of the sample performed very poorly, only 2 or 3 children falling in the normal range.

Figure-ground

Twelve children were within the age range for which standardised scores could be obtained and 3 of these were more than 2 SD below the mean.

Figure 7.1: **Performance of spina bifida children on screw test**

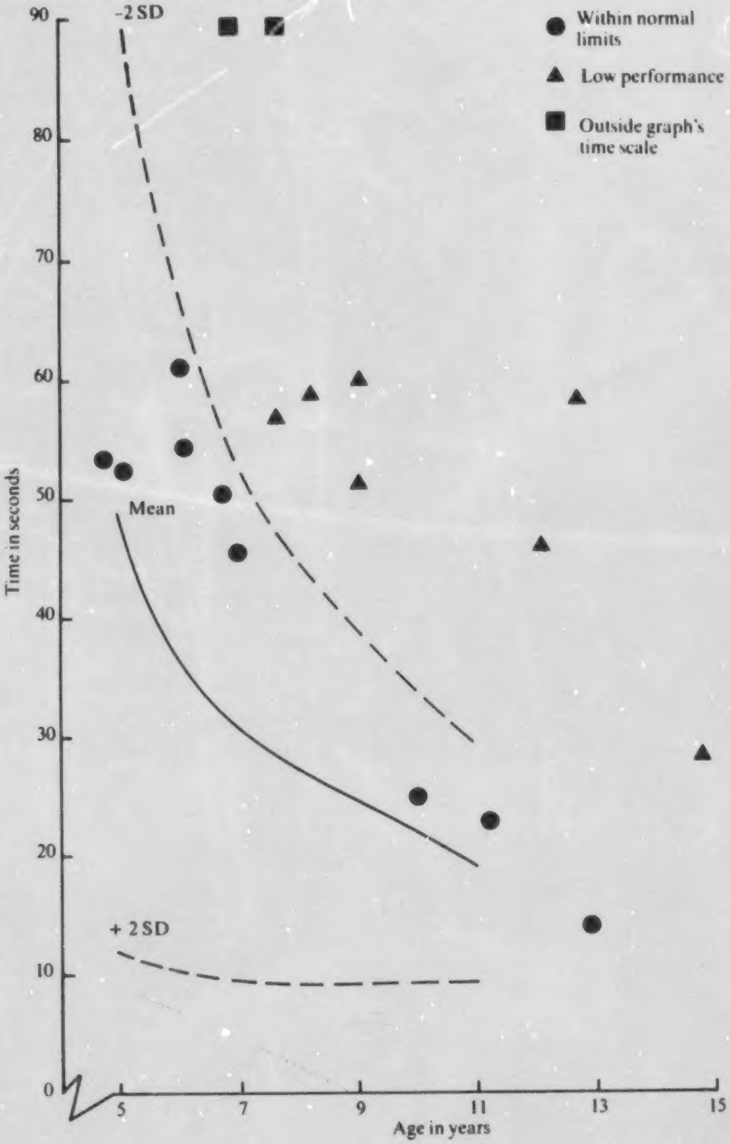


Figure 7.2: **Performance of spina bifida children on hand function: small objects**

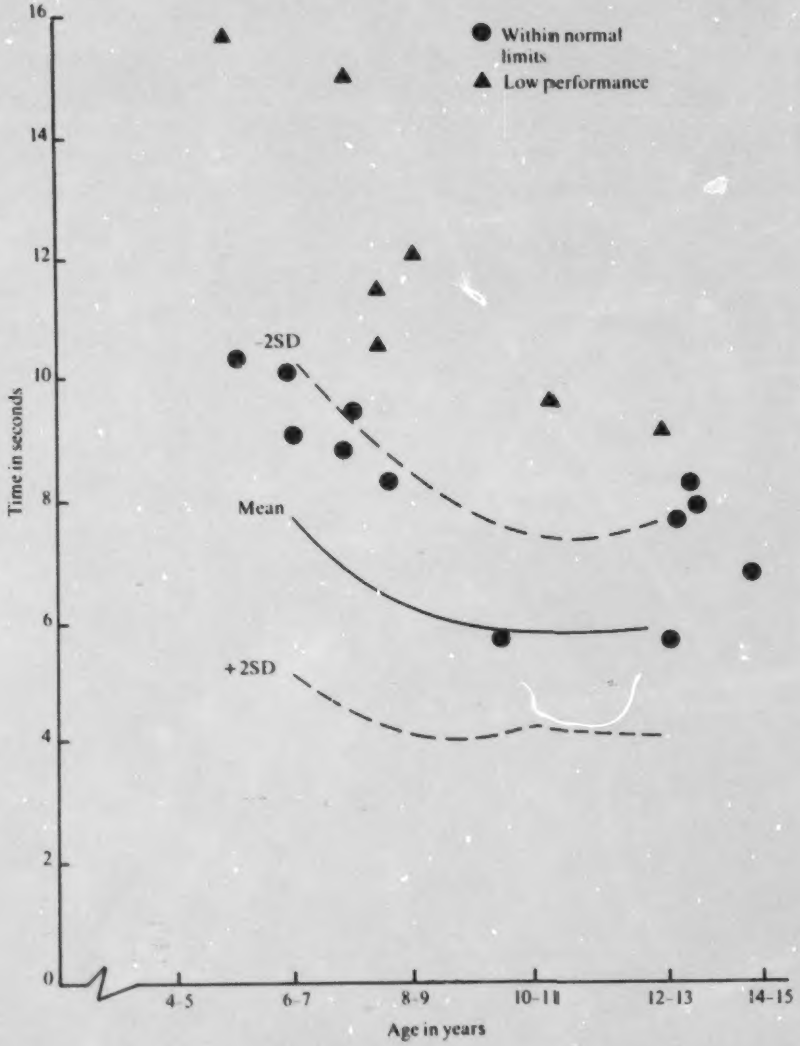


Figure 7.3: **Performance of spina bifida children on hand function: card turning**

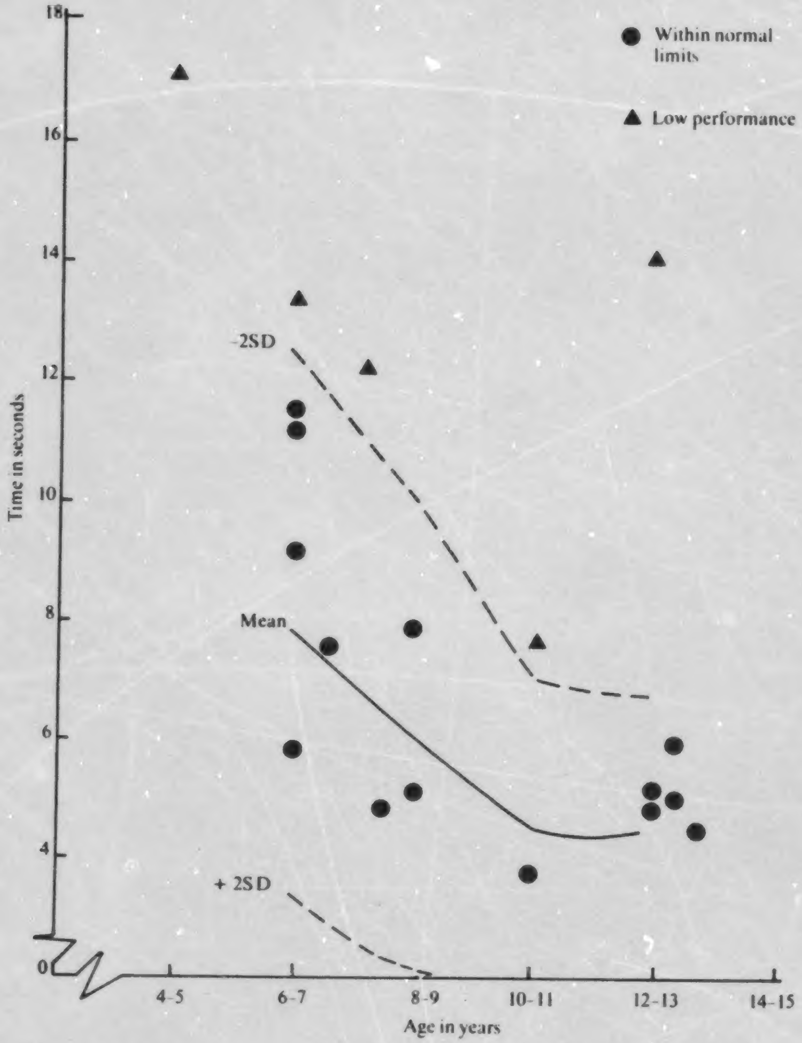


Figure 7.4: **Performance of spina bifida children on hand function: checkers**

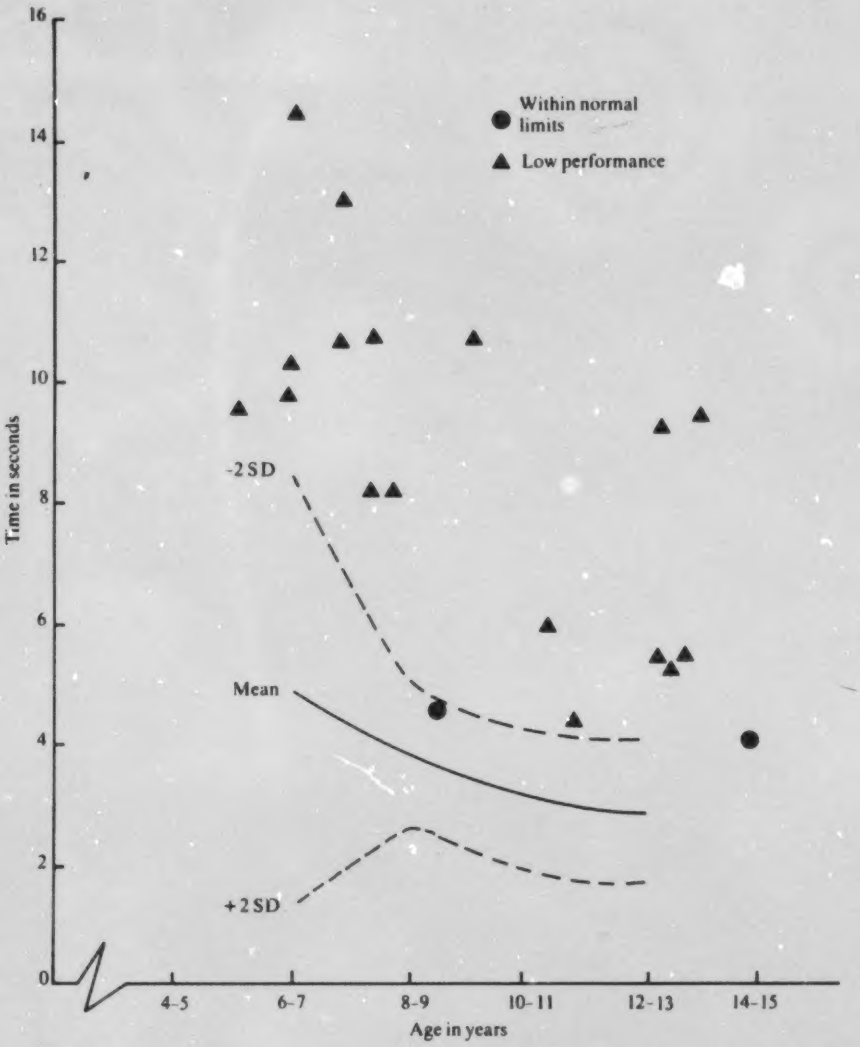


Figure 7.5: **Performance of spina bifida children on hand function: simulated feeding**

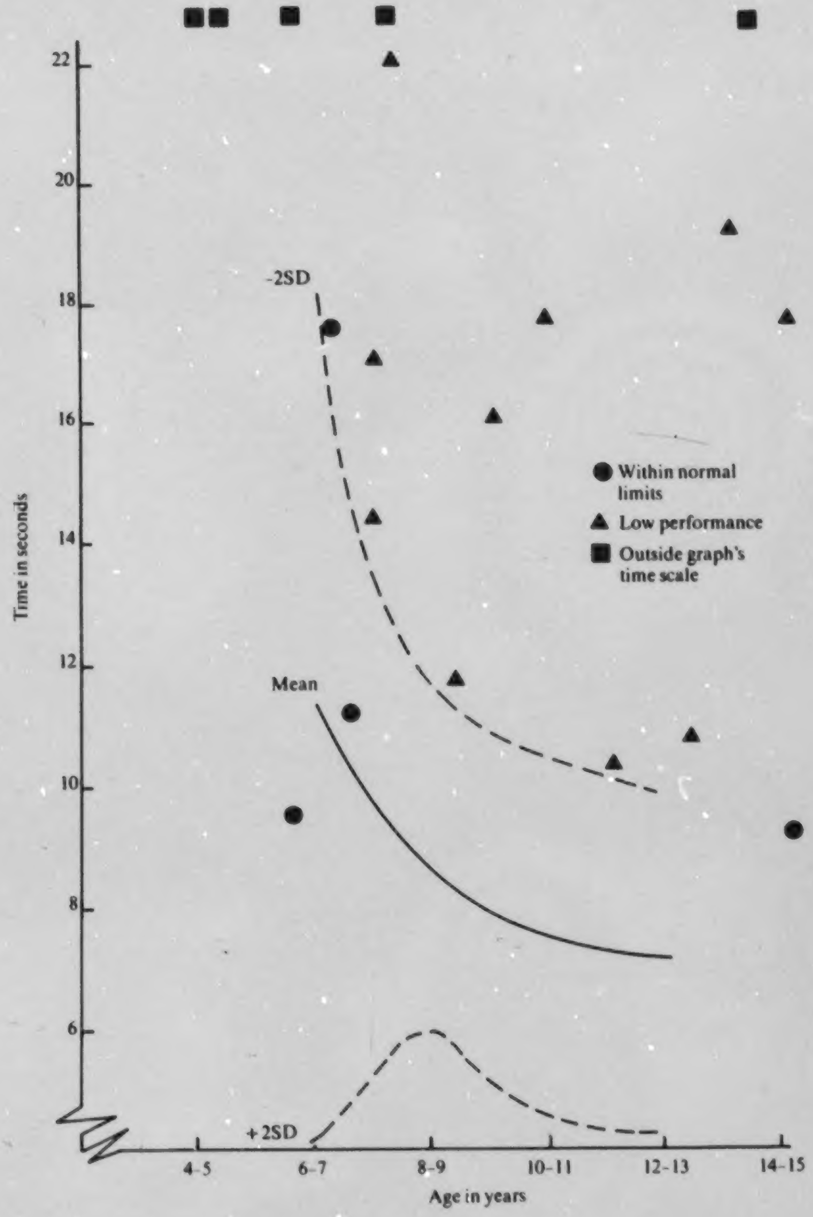


Figure 7.6: **Performance of spina bifida children on hand function: large light objects**

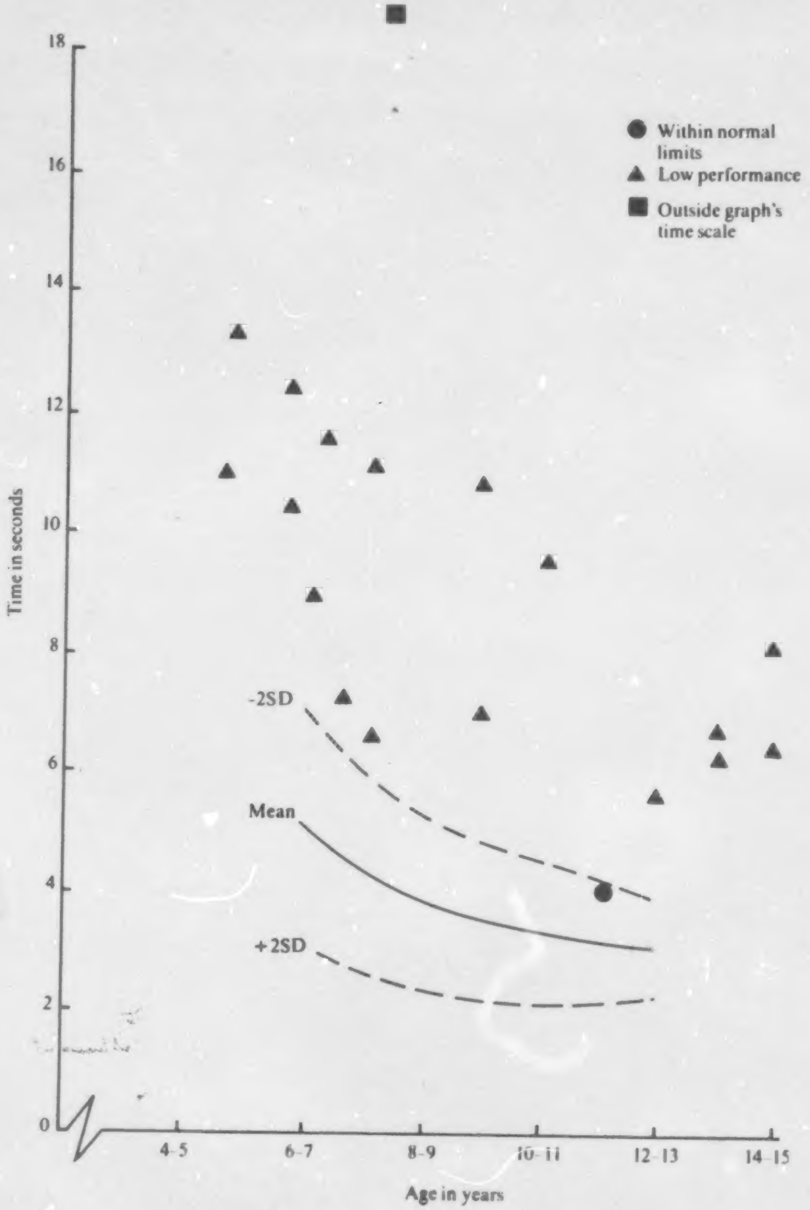


Figure 7.7: **Performance of spina bifida children on hand function: large heavy objects**

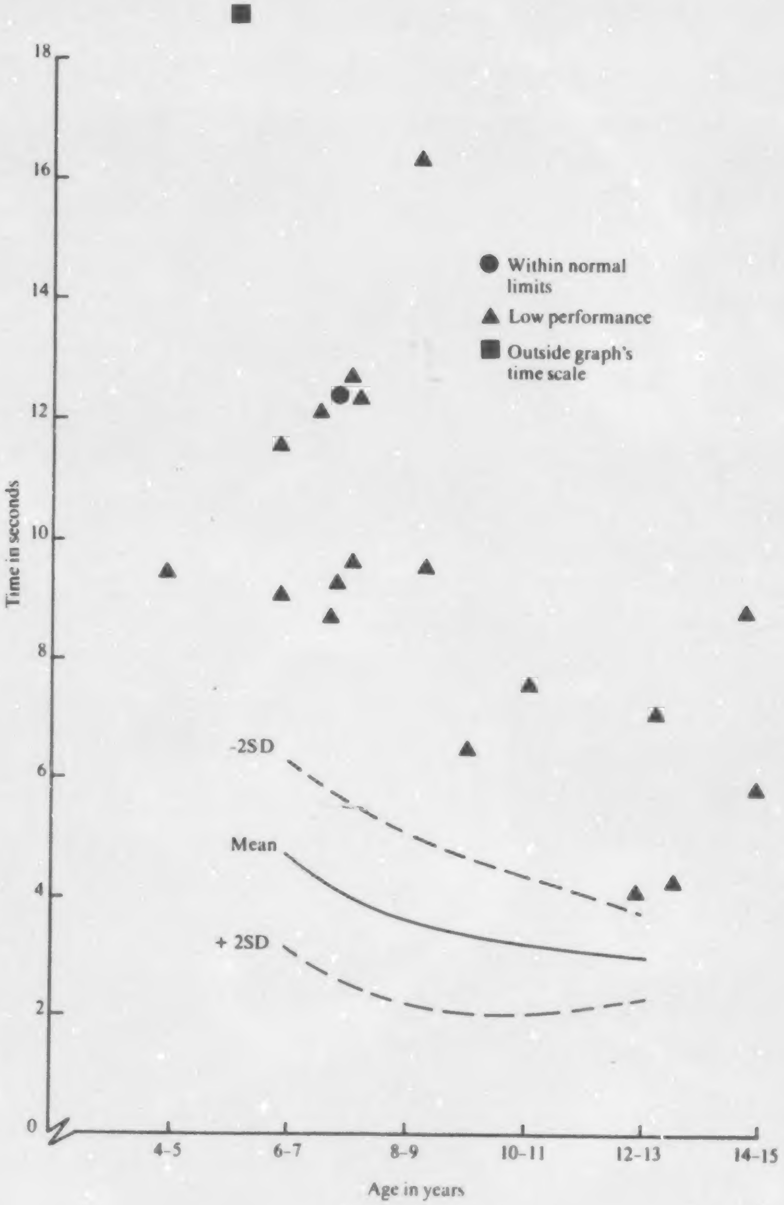
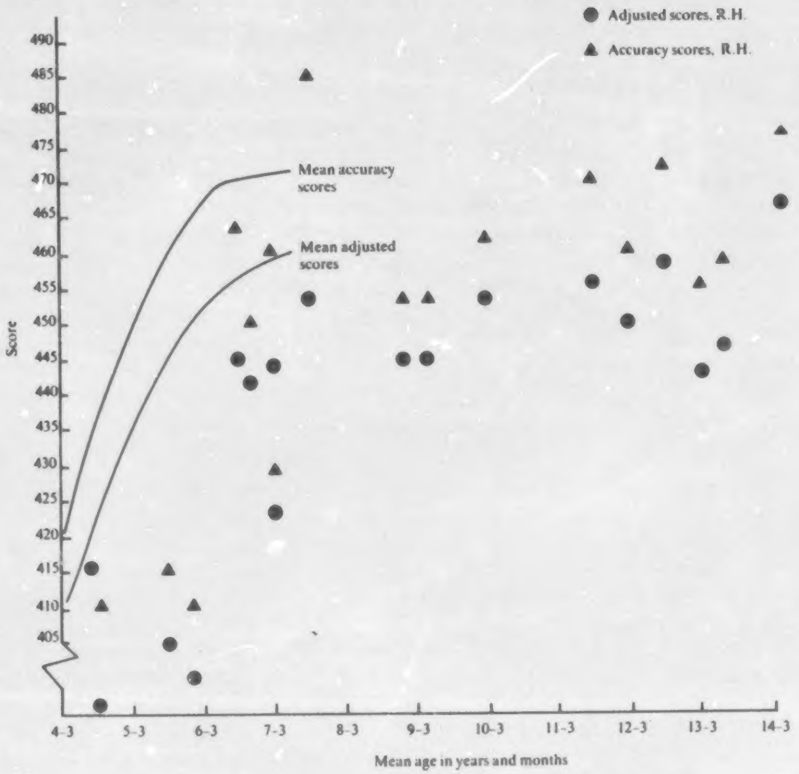


Figure 7.8: **Mean SCMAT scores of more accurate hand**



Motor Accuracy

Interpretation of the scores on this test were again restricted by the limited age range for which standardised scores were available. A graphical technique was used to represent performance, using a diagram from page 5 in the Test Manual (Figure 7.8). Again most children seemed to perform at a low level. The 2 spina bifida children without hydrocephalus were somewhat better than most of the other children on this test.

Table 7.2: **Correlations among left and right hands for selected motor tests**

Test	*r*	*Test*	*r*
Taylor 1 (Common objects)	.43	SC motor accuracy (time)	.82
Taylor 2 (Card turning)	.80	SC motor accuracy (accuracy)	.84
Taylor 3 (Checkers)	.68	SC motor accuracy (adjusted)	.85
Taylor 4 (Feeding)	.57		
Taylor 5 (Light objects)	.72		
Taylor 6 (Heavy objects)	.80		

Handwriting

No data are available to permit a normative interpretation of the handwriting scores. However, handwriting and the adjusted SC motor accuracy score were observed to correlate, −.81, indicating that the motor accuracy test may be measuring skills similar to those needed for handwriting (Table 7.3).

Correlation among the variables

Table 7.2 contains correlations between right- and left-hand performance on the 6 Taylor hand function tests and the 3 SC motor accuracy measures. These correlations range from 0.43 to 0.85, indicating a moderate to high degree of association between left- and right-hand performance.

Table 7.3 presents correlations among selected variables. Correlation coefficients are generally fairly large, indicating that the tests are measuring related skills. However, the screwing task has low correlations with other tests except the Taylor large heavy objects test. Most tests correlate between 0.4 and 0.8 with the handwriting task, indicating the potential utility of the tests in future studies of handwriting performance.

7.4 DISCUSSION

The results of the pilot study were made difficult to interpret by a number of factors. First, any influence on low I.Q. on motor performance could not be allowed for in interpreting the findings. Secondly, the wide age range of the sample found many tests were being used beyond their intended age range. Future research should endeavour to use samples with more nearly normal distribution of I.Q. and to be of a less extreme chronological age.

Thirdly, several useful measures were either standardised or standardised over only a limited age range. Standardisation of these and other tests with accompanying study of their reliability and validity would certainly benefit researchers.

Fourthly, the influence of hydrocephalus could not be established, since only 2 spina bifida children were known to have no hydrocephalic complications. Though it would be difficult to find research samples of sufficient size, studies of (i) hydrocephalus with spina bifida, (ii) hydrocephalus without spina bifida, and (iii) spina bifida without hydrocephalus might be helpful in identifying the conditions in which fine motor difficulties occur. Also, the stage at which shunts are inserted to control hydrocephalus may be an important variable.

Fifthly, there is a need for studies of tests of fine motor skills and related abilities to be studied in samples of normal children at various age levels.

In those cases where concern is felt for fine motor skills in spina bifida children, early intervention would seem a good policy, taking into account the plasticity of the nervous system in the first years of life. Eye–hand co-ordination and use of the hands for motor tasks should be encouraged as soon as possible. In these early years, when the child's condition is being modified by surgery of many kinds, intervention with a program such as that of Rosenbaum, Barnitt & Brand (1975), which is designed to overcome the effects of impaired mobility, could have many benefits. Not only might co-ordination and skill be encouraged, but the child's personality and behavioural characteristics may be modified.

The archocerebellum, which is a major component of the vestibular system, is deformed and histologically disrupted along with the brain stem in Arnold Chiari malformation. It seems possible, then, that balance is affected and that the techniques of Ayres (1976) using sensory intergration at the brain stem (reticular system) level might benefit these children.

Table 7.3: **Correlations among selected variables**

	1	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*
1. Screwing	1.00	.27	.07	.28	.37	.31	.51	–.01	–.01	–.42	–.42	.24
2. Taylor 1 LH (Objects)		1.00	.84	.71	.66	.60	.36	–.43	–.22	–.37	–.36	.61
3. Taylor 2 LH (Cards)			1.00	.78	.63	.65	.25	–.46	–.20	–.51	–.51	.48
4. Taylor 3 LH (Checkers)				1.00	.60	.74	.62	–.65	–.04	–.69	–.75	.68
5. Taylor 4 LH (Feeding)					1.00	.70	.70	–.36	–.25	–.56	–.57	.63
6. Taylor 5 LH (Light objects)						1.00	.56	–.53	–.25	–.70	–.71	.81
7. Taylor 6 LH (Heavy objects)							1.00	–.24	–.09	–.62	–.66	.60
8. Figure Ground								1.00	.16	.56	.58	–.44
9. Motor accuracy (time) LH									1.00	.52	.36	–.51
10. Motor accuracy (accuracy) LH										1.00	.98	–.70
11. Motor accuracy (adjusted) LH											1.00	–.81
12. Handwriting												1.00

The neurophysiological benefits of Margaret Rood's techniques applied through spinal cord sensory-motor pathways to the brain stem could also benefit balance and muscle tone. The opinion was formed that some of the children tested were hypotonic, the paleocerebellum being implicated.

It is interesting to note that all of the children tested had good righting reactions of the head in the vestibular test, and that none of them seemed unduly anxious during the test. Perhaps this could be explained by the training they had received in preparation for walking, and fine grain testing of vestibular function could prove interesting among children with spina bifida.

Only 1 girl and 1 boy tested showed definite signs of ataxia, the motor cortex neo-cerebellar feedback loop being implicated here. Peto techniques using cortical control and the association between hand skills and language could be of benefit for these cases.

The children were not tested for evidence of primitive reflexes, and the literature (see Holgate 1970) indicates that with the shunting of hydrocephalus, these usually disappear reasonably early. However, Bobath techniques using the automatic postural responses of the cerebellum and brain stem as they react to position and movement could also be beneficial.

All the children used mature grips, many of the younger ones lacking refinement. There was no evidence of 'split brain' signs indicating agenesis of the corpus callosum.

No attempt was made in the present study to explore the hand dominance of the children tested, although this factor should receive attention in future studies. Several children appeared to be ambidextrous, but 1 child showed strong dominance in her refusal to attempt the motor accuracy test with her non-dominant hand.

7.5 SUMMARY

The present study illustrates some of the difficulties associated with systematic investigation of small clinical groups of handicapped children. The very small pool of spina bifida children available for study prevented the use of a representative sample. Future studies using samples which are more homogeneous in age and intelligence may require investigators to combine samples from several large cities. This practice, however, might be contra-indicated if different children's hospitals adopt different criteria for the surgical treatment of spina bifida. It may be fruitful to explore the use of carefully documented individual case studies, perhaps of a longitudinal nature, in order to conduct research within the spina bifida population.

A clear picture of the occurrence of fine motor and related difficulties in spina bifida and hydrocephalus may have to await theoretical advances in the neurophysiology of control of skilled movements.

CHAPTER 8

PARENTS' EXPERIENCES DURING THE SCHOOL YEARS

8.1 INTRODUCTION

Following the first years of the life of a handicapped child and the parents' particular need for help and support during that time, onset of the school years brings a period of possible concern in the lives of the parents and their child. Soon after the birth, the parents of a handicapped child turn their attention to the future and seek information and advice about the schooling and long-term development of their child. This is especially true of parents of children with severe physical and multiple disabilities, such as those which often characterise children with neural tube defects.

This section of the report is especially concerned with the school years of the handicapped child and provides information from the 130 parents interviewed on their experiences.

8.2 EARLY SCHOOLING ARRANGEMENTS

Of the 130 parents interviewed, 51 had a spina bifida or hydrocephalic child about to be enrolled in a school or pre-school. Forty-six (92%) of the parents responding had already decided on which pre-school or school the child would attend. Only 4 parents were undecided on this matter. Of those parents where a decision was appropriate about the primary-level school the child would attend, most (83%) planned enrolment in a local State or private school. In contrast, only 10.6 per cent (5 parents) planned that their child should attend a special school, while 3 families were still unsure about primary school enrolment (Table 8.1).

Table 8.1: **Type of school placement planned**

Type of school nominated	*No. of parents*	*Per cent of group*	*Per cent of valid cases*
Regular state school	37	28.5	78.7 } 83.0
Regular private school	2	1.5	4.3 }
Special school	5	3.8	10.6
Unsure about school placement	3	2.3	6.4
Pre-school decision	4	3.0	–
Not applicable only (already at school)	79	60.8	–
Totals	130	100.0	100.0

The question of whether or not special schooling had been suggested to the parents was also explored. Although 5 parents planned on special school attendance, another 7 reported that they had been advised that special schooling would be best for their child. Of these 12 parents, 3 reported that special schooling was suggested by a medical practitioner and 6 reported that it was suggested by other professional persons including therapists and teachers. Of the remaining 3 parents in this group, 1 was advised by a relative to place the child in a special school, 1 was advised by 'people who don't know or understand the child', while the other source of advice was not disclosed. The parents reported a considerable range of feelings about special school placement and these are discussed later in this chapter.

8.3 SCHOOL ATTENDANCE AND ACHIEVEMENT

The mothers of the 130 children reported that they attended various types of schools, as set out in Table 8.2. Compared with the data reported in Chapter 3, a higher proportion of this group (those whose parents were interviewed) attended regular schools. Of the 77 children enrolled in primary and secondary-level schools (excluding pre-schools), 56 (72.7%) had had some pre-school experience, ranging from less than 6 months by 1 child to from 18 to 24 months for 26 of the children. In this context, pre-school experience was defined as attendance at a play group, kindergarten or pre-school. The children were equally divided between attendance on 2–3 occasions a week and 4–5 times a week.

Of the 77 children then attending primary- or secondary-level schools, all but 18 (23.4%) began their formal schooling at the usual age—in their 6th year—while 17 (22.1%) began in their 7th year, 1 year later than average, and 1 (1.3%) began 2 years later than average.

Table 8.2: **Type of school attended by the 130 children**

Type of school	*No. of children*	*Per cent of group*	*Per cent of valid cases*
At regular pre-school	12	9.2	12.8
At special pre-school	5	3.8	5.3
At regular primary school	46 } 55	35.4	48.9 } 58.5
At regular secondary school	9	6.9	9.6
At special school	22	16.9	23.4
Too young to attend	35	26.9	
Too handicapped (bedfast)	1	0.8	
Totals	130	100.0	100.0

Examination of Table 8.3, in comparison with Table 8.2, shows that there has been little change in the numbers attending regular and special schools from their 1st school admission to the time of the survey, an overall effect of 2 children moving from special to regular school. However, 28 children had had a change of schooling since 1st enrolment. Of these, 10 had graduated to high school, 8 had moved to special schools, 5 changed schools because of a change of residence, and 5 made changes for reasons unrelated to the child's disability.

Parents were asked to give an assessment of the school performance of their children. Table 8.4 indicates that 46 per cent (35) of parents rated their child's scholastic achievement as average and 37.5 per cent (30), below average. These estimates compare reasonably well with those reported in Chapter 6 made by teachers for 116 children on the basis of other children of the same grade/age. If anything, the parents tended to slightly overestimate the academic achievements of their children in comparison to the teachers.

Table 8.3: **Type of school attended on first admission(*a*)**

Type of school	*Metropolitan*		*Other urban*		*Rural*		*Total*	
	No.	*%*	*No.*	*%*	*No.*	*%*	*No.*	*%*
Regular local school	26	66.7 (33.8)	19	65.5 (24.7)	8	88.9 (10.4)	53	(68.8)
Special school	13	33.3 (16.9)	10	34.5 (13.0)	1	11.1 (1.3)	24	(31.2)
Totals	39	100.0 (50.6)	29	100.0 (37.7)	9	100.0 (11.7)	77	(100.0)

(*a*) Percentages are for each location, except those in parentheses, which are for the total group.

Table 8.4: **Parents' assessment of school achievement: compared with children of the same age**

Achievement assessment	*No. of children*	*Per cent of group*	*Per cent of valid cases*
Above average in scholastic achievement	10	7.7	13.2
Average in scholastic achievement	35	26.9	46.0
Below average in scholastic achievement	30	23.1	39.5
No opinion expressed	2	1.5	1.3
Not applicable	53	40.8	
Totals	130	100.0	100.0

8.4 THE QUESTION OF SPECIAL SCHOOLING

The question of special schooling can be a vexed one for many parents of a handicapped child. As discussed earlier in this report, there is a distinct trend for spina bifida/hydrocephalic children to be enrolled by their parents in regular schools. Fifty-eight per cent of all children in schools in the total study group were enrolled in regular schools, compared with 42 per cent in special school settings. Likewise, Table 8.3 shows that of the 77 children (out of the 130 whose parents were interviewed) who had been enrolled in primary-level schooling, 69 per cent had initially been placed in a regular school and only 31 per cent in a special school.

Nevertheless, the question of special schooling is likely to arise at some time before or during the school life of the disabled child. Of the 130 parents interviewed, 52 (40%) stated that the suggestion to enrol their child in a special school had been made. The suggestion was more likely to occur during the primary-school years than at any other time, though the proportion of parents to whom the suggestion was made increases with the age group of the children, even though total enrolments were smaller among older children. This phenomenon needs to be monitored carefully, as it may indicate deterioration in the quality of educational experience with increasing age.

Suggestions about attendance at special school came from a range of sources, but mostly from professionally qualified people. Of these, those with medical and nursing backgrounds made up the largest group (36.5%). Therapists were also named as a source of advice to parents (15.4%), while educationists advised special schooling in 19 per cent of cases (27% of those advised by professional persons). Relatives and friends, and other parents of a handicapped child, suggested special schooling in 19 per cent of cases.

Parents' attitudes to special schooling are known to vary. In this study, 123 of the 130 parents interviewed expressed an attitude and the majority (61%) had a positive approach to this form of schooling. Only 28 parents (22.8%) expressed a negative attitude, while 20 (16.3%) were ambivalent in their approach. A comparison of parents' attitudes by age groups indicated that the highest proportions of parents who regarded special schooling positively had handicapped children aged between 12 and 20 years (87.5%) or aged in the pre-school years (66.7%). For the other age group (6–12 years), the views of parents were fairly evenly divided between a positive attitude and those with negative or ambivalent views on special schooling.

A large number of those who expressed a positive attitude to special schools did so with the reservation that such schools were good for those that need them but **not** for their child. Fifteen of those against special schools (53.6%) considered that they had lower educational standards, while 5 (17.8%) believed that there was a stigma associated with attendance at a special school. Many parents regarded special schools as schools catering for intellectual handicap rather than for physical handicap.

Seventy parents (90.9%) of the children attending regular primary and special schools believed their child was appropriately placed. Reasons for this included that the child was happy there, that the parents were satisfied with his/her academic progress and teacher acceptance, and that they believed firstly in integration — all were frequently given. A number of these parents also mentioned difficulties encountered, mainly of physical access and distance from school but did not consider them serious enough to warrant changes of placement.

Five parents (6.5%) expressed the view that their child was inappropriately placed in school. Two of the children were day pupils in special schools, and 1 parent was seeking to arrange admission to a private school the next year. The other was at a residential pre-school and her mother was anxious to have her at home. Transfer was expected to be arranged after further medical treatment was completed. The remaining 2 parents expressed a desire for improved services but not a change of school. One mother was dissatisfied with transport arrangements to the opportunity[1] school her child attended (a hydrocephalic child with some motor problems, travelling by bus). This mother sought taxi transport. The mother of a child in a regular primary school sought an expanded visiting-teacher service to that school.

The parents of 91 per cent (70) of the children in regular and special schools (excluding pre-schools) had had contact with the staff of their child's school. Of these parents, one-third had school contact more than 3 times a year, but nearly half had contact not more than once a year. Most consultation was with the child's class teacher. The school principal did not appear to be a major source of regular contact with the parents.

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[1] Now referred to as special schools.

8.5 PARENTS' MANAGEMENT OF CHILD

8.5.1 Management of incontinence

Of the 130 children whose parents provided information for this section of the report, 90 were incontinent of bladder, 26 were continent and 14 were too young for this aspect to be judged. Some 60 per cent (78) of this group used artificial appliances to establish and maintain continence of the bladder; 9 children who were not continent did not use artificial means of control. The parents of the 35 children reporting that artificial means were not employed were asked to indicate the degree of continence achieved by the children. This was stated to be:

Child completely continent	8 children
Child continent except if ill, excited or cold	6 children
Continence normal for age	2 children
Child still young, but continence confidently expected	3 children
Child partially trained	2 children
Child totally incontinent	7 children
Child uses napkins, plastic devices, but largely continent	7 children

Table 8.5 sets out the methods of coping with bladder incontinence by the 90 children employing aids or other approaches. The information is given by 4 age groups and by sex of the children. Urinary diversion was by far the most common (46.7%) method employed, followed by the use of napkins (30%) and supra-pubic devices by boys (21%). Only 2 girls employed intermittent self-catherisation. It will be noted that urinary diversions were not used with children under 3 years, and no adolescents above 12 years of age coped with incontinence of the bladder by the use of napkins.

Incontinence of the bowel was reported by the parents for 81 of their children, with 17 children being too young for the level of continence to be determined. Dietary control was used in nearly half (47%) of the relevant cases and taping of the anus in 8.7 per cent (7). The parents of the remaining 36 children (44.4%) relied on a variety of methods to attain control including daily enema, suppositories, manual removal, aperients and regular timing and straining.

8.5.2 Management of immobility

For the present group of 130 children, 26 (20%) were unable to walk and the remaining 104 children were mobile to some degree; 72 (55.4%) wore calipers or used mobility aids. Table 8.6 shows that 61 of the group used right and/or left short or full-length calipers with or without the use of crutches. By far the most common combination was the use of full-length right and left calipers with crutches, as employed by 28.5 per cent of the group of 130 children, or 51 per cent of those who required mobility aids. The 26 children unable to walk generally relied on wheelchairs (or other wheeled aids) for mobility. These were distributed by age as follows:

Under 3 years	0 children
3 to 5 years	5 children
6 to 11 years	16 children

Table 8.5: **Methods of coping with incontinence of bladder**

Methods		*Under 3 years*			*3 yrs to 5 yrs 11 mos*			*6 yrs to 11 yrs 11 mos*			*12 yrs to 20 yrs*			*All children*		
		Boys	*Girls*	*Total*	*Boys*	*Girls*	*Total*	*Boys*	*Girls*	*Total*	*Boys*	*Girls*	*Total*	*Boys*	*Girls*	*Total*
Napkins	*No.*	2	12	14	3	3	6	5	2	7				10	17	27
	%	2.2	13.3	15.5	3.3	3.3	6.7	5.6	2.2	7.8				11.1	18.9	30.0
Urinary	*No.*				5	4	9	8	17	25	3	5	8	16	26	42
diversion	%				5.6	4.4	10.0	8.9	18.9	27.8	3.3	5.6	8.9	17.8	28.9	46.7
Intermittent	*No.*		1	1							1	1	2	1	2	2
self-catherisation	%		1.1	1.1							1.1	1.1	2.2	1.1	2.2	2.2
Supra-pubic	*No.*				5		5	10		10	4		4	19		19
device	%				5.6		5.6	11.1		11.1	4.4		4.4	21.1		21.1
	No.	2	13	15	13	7	20	23	19	42	8	6	14	45	45	90
Totals	%	2.2	14.4	16.7	14.4	7.8	22.2	25.6	21.1	46.7	8.7	6.7	14.4	50.0	50.0	100.0

Table 8.6: **Type of caliper worn or aids used**

Type of caliper or aid	*No. of children*	*Per cent of group*	*Per cent of valid cases*
Full-length (R + L) calipers + crutches	37	28.5	51.4
Full-length (R or L) caliper + crutches	1	0.8	1.4
Short (R + L) calipers + crutches	8	6.2	11.1
Short (R + L) calipers, without crutches	5	3.8	6.9
Short (R or L) calipers + crutches	1	0.8	1.4
Short (R or L) calipers, without crutches	9	6.9	12.5
Crutches, walking-stick or walking-frame, without caliper(s)	11	8.4	15.3
Not applicable	58	44.6	
Totals	130	100.0	100.0

8.6 SOCIAL ADJUSTMENT OF CHILD

The parents of children attending school were asked to report on friends at school and aspects of the play and other contacts their child had with their friends. Nearly half (49.4%) of the group at school had several friends and almost an equal number had a few friends. Only 5 children (6.2%) were reported not to have any friends at school.

Most (53.2%) friends of the target group were school-friends, some (12.7%) were described as neighbourhood friends. It will be noted that multiple responses occurred in nearly a sixth (12.7%) of the valid cases (Table 8.7). Half (49.4%) of the group also spent time with their friends out of school hours, while about a quarter did not. A small group (6.3%) reported that distance prohibited this contact.

Table 8.7: **Place of meeting friends**

	No. of children	*Per cent of group*	*Per cent of valid cases*
School-friends	42	32.3	53.2
Friends of the family	1	0.8	1.2
Neighbourhood friends	10	7.7	12.7
Sunday school friends	1	0.8	1.3
Multiple response	14	10.8	17.7
Other	11	8.4	13.9
Not applicable and children below school age	51	39.2	
Totals	130	100.0	100.0

Of the 70 parents with children in the group of 130 who were aged 6 years and over, only 40 parents (57%) gave details of the frequency of play periods with school-friends out of school hours. Ten per cent (7 children) of this group of 70 children enjoyed daily play periods. One fifth (21%) played with friends out of school hours less than once a week. The types of play activities engaged in were divided between primarily outdoor activities (43%), primarily indoor activities (28%) and most usually indoor and outdoor activities (29%). Some 58 per cent spent some time playing at their friends' houses. Eighty-seven per cent of those with siblings spent time playing with them.

Only 4 families reported that it was not possible for the family to go on outings together for reasons related to their spina bifida child. The frequency of outings taken by the families was described by them to be 'only occasional', 'fairly often' and 'frequent' by equal numbers of parents.

The parents also reported on the presence of behaviour and/or emotional difficulties in their physically handicapped children. One third of the group believed such difficulties existed in their child, and in 75 per cent of these cases the difficulties were regarded as being greater than those experienced by the children's peers.

The most frequently reported difficulties centred on the children being emotional, fearful and frustrated. Nine parents recognised frustration as being a prime cause of many problems. Fifteen others considered their children 'highly strung', easily upset, afraid or emotional, and 3 reported their child was withdrawn. Seven children questioned their physical condition (and had not yet received satisfactory answers). Two children were especially upset by separation from their parents and another 2 used their disability to manipulate the parents and others. One child was reported to be hyperactive, 1 was distinctly resentful, and 1 suffered from lack of concentration. Only 1 parent reported that the children at school 'mocked' her child's disability, calling her 'nappy pants'.

Two-thirds of the parents of children with emotional and behaviour difficulties estimated that they arose from the child's disability. A further 16 per cent attributed the problems to the subject's personality or stage of development, while 13 per cent did not suggest a cause of their child's problems.

The parents of more than half (53.1%) of these children had not sought help and advice in managing the problems experienced, but of those who had (23 parents), help had mainly been sought from medical practitioners (43.5%), the Queensland Spina Bifida Association (26.1%) and from teachers (17.4%).

Of the 26 parents (53 per cent of those reporting difficulties) who had not sought help, nearly two-thirds reported that assistance was not required. Of the remainder, 4 parents did want help with the problems and 5 were uncertain about the need for help and advice.

However, in an overall estimate of their child's situation, 126 (96.9%) were reported by their parents as usually being happy. The exceptions were 2 children in kindergarten reported to cry a lot, 1 child with hydrocephalus in a regular school finding peer pressure too great and a fourth child, a girl in a special school, reported by her father to have become withdrawn and to have 'lost interest in life'.

It was noted earlier that of the children reported to have emotional and behavioural problems, two-thirds (65.4%) of these difficulties were thought to be due to the child's disability. Of the group of 130 children and adolescents, 58 per cent (76) of parents also reported that the child's disability had an effect on his/her relationship with other children. Seventy-three parents attempted to analyse this situation and 62 per cent of these reported that the problems arose because of lack of mobility in their child. Other parents considered the problems were associated with the disability itself, while a few parents believed that the difficult relationships with peers were due to problems of their child's personality. They saw their child behaving in an unacceptable way because of the disability.

The most frequent response, to do with the effects of spina bifida or mobility, was that 'he/she can't keep up with the others'. The ensuing problems were seen to be a result of frustration. Sometimes this was evidenced in withdrawal, sometimes in attention-seeking behaviour or in anger. Of these children, however, the parents reported that 10 apparently insisted on being included in those activities that interested them, and that their integration into the non-handicapped group was quite satisfactory.

8.7 SUMMARY

It is clear from the parent interviews that there were many important decisions about the schooling of the handicapped children which had been made with relatively little professional support. The parents' decisions on school placement appear to have been soundly based with almost no exchange between special and regular placement occurring. In terms of their attitudes, parents of spina bifida children exhibited much the same views as parents in general, with a tendency to link the need for special schooling with intellectual handicap more than physical handicap.

It seems significant that parent–school contact was mostly with the class teacher, rather than principal or support staff (guidance officer, visiting teacher or remedial/resource teacher). Much more needs to be learned about the dynamics of the interaction between parents of handicapped children and the staff of schools. In view of present support for increased integration of the handicapped, detailed observational studies of the nature of the interaction between staff and parents might lead to more appropriate procedures being adopted by school systems, to the preparation and use of parent information systems and to the routine exercising of partnership by both groups.

Management of bowel and bladder incontinence, and of mobility problems, constitute major areas of concern to the parents. Clearly, the availability of appropriate paramedical support services would ease the burden of responsibility for management of these problems.

While substantial proportions of the spina bifida children appeared to enjoy normal social relationships, a small number appeared to be isolated and at risk for social maladjustment. That a third of the parents indicated some behaviour or emotional difficulties in their spina bifida children is of considerable concern, and most had not sought help. Again, a more extensive support service which co-ordinated school and home in the management of the children would offer valuable and needed assistance to parents who were concerned over their child's emotional welfare. The parents' judgment that mobility was likely to be the major source of the child's unhappiness deserves attention. It seems clear that more needs to be done, both in school and out, to increase the range of activities in which physically handicapped children take part. Such increased mobility could be realised through the provision of aids and equipment, modifications to buildings in school, home and community, and community education on the nature and needs of handicapped persons.

CHAPTER 9

LONG-TERM CARE FOR SPINA BIFIDA AND HYDROCEPHALIC CHILDREN

As indicated in previous chapters, especially Chapter 4, children and adults experiencing spina bifida and/or hydrocepahlus who were in long-term care made up a significant group in this study. Table 4.6 recorded that 34 such persons were identified in long-term residential locations provided by government and non-government agencies in Queensland. In addition, others were living at home or in a residential school, both of which were employed as alternate forms of long-term residential care.

This chapter briefly surveys these subjects, seeks to identify some of their characteristics, and comments on their needs.

9.1 GENERAL CHARACTERISTICS

Table 9.1 gives details of the age and sex of the children and young people. As would be expected, in view of the lowered life expectancy of many profoundly handicapped children, the largest numbers of cases in long-term care were in the lower age groups, although there were also significant groups at each age level to 20 years. The subjects were about equally divided between male and female.

Details of diagnosis are given in Table 9.2. The predominance of hydrocephalic cases is very marked in this population, a situation not observed in any other sub-group in this study. None of the subjects was experiencing spina bifida only, and only 5 (12%) of the group had both spina bifida and hydrocephalus. Of the cases with spina bifida, only 2 had had the lesion closed. All 39 subjects, on the other hand, had hydrocephalus.

Further information on this group indicated that the hydrocephalus experienced by the subjects was likely to be more severe than for other groups, and not controllable by shunting. An analysis (Table 9.3) of diagnosis by age indicates no significant distribution trends.

Table 9.1: **Age and sex of the subjects**

	Males		*Females*		*Total group*	
Age groups	*No.*	*%*	*No.*	*%*	*No.*	*%*
Birth to 4 yrs 11 mths	7	18.0	6	15.4	13	30.9
5 yrs to 9 yrs 11 mths	7	18.0	3	7.7	10	25.6
10 yrs to 14 yrs 11 mths	6	15.4	3	7.7	9	20.5
15 yrs to 19 yrs 11 mths	1	2.5	5	12.8	6	20.5
20 yrs to 24 yrs 11 mths	1	2.5	0	0.0	1	2.5
Totals	22	56.4	17	43.6	39	100.0

Table 9.2: **Diagnostic classification of subjects in long-term care**

Diagnosis	*No. of subjects*	*Per cent of group*
Spina bifida only	0	0.0
Spina bifida and hydrocephalus, with shunt	2 } 5	5.1 } 12.8
Spina bifida and hydrocephalus, without shunt	3	7.7
Hydrocephalus only, with shunt	15 } 34	38.5 } 87.2
Hydrocepahlus only, without shunt	19	48.7
Totals	39	100.0

Table 9.3: **Diagnostic classification of subjects: by age**

	Age levels					
Diagnosis	*< 4 yrs 11 mos*	*5 yrs to 9 yrs 11 mos*	*10 yrs to 14 yrs 11 mos*	*15 yrs to 19 yrs 11 mos*	*> 20 yrs*	*Total group*
Spina bifida only	0	0	0	0	0	0
Spina bifida and hydrocephalus, with shunt	0	0	1	1	0	2
Spina bifida and hydrocephalus, without shunt	2	1	0	0	0	3
Hydrocephalus only, with shunt	5	4	4	1	1	15
Hydrocephalus only, without shunt	6	5	4	4	0	19
Totals	13	10	9	6	1	39

Table 9.4: **Mobility characteristics of the subjects**

Degree of mobility	*No. of subjects*	*Per cent of group*
Too young to determine(a)	23	59.0
Independent in walking	10 } 13	25.6 } 33.3
Independent with walking-aid	3	7.7
Dependent	3	7.7
Bedfast	—	—
Totals	39	100.0

(a) Effectively bedfast when surveyed, but some may obtain a degree of mobility in future years.

The data on the mobility characteristics of this group indicated a large proportion (23, or 59%) who were judged by informants to be too young to have their mobility determined (Table 9.4). This information needs to be compared with the age distribution of the subjects, as only 23 cases are recorded in Table 9.1 to be under the age of 10 years. It must be concluded that although it was judged for developmental reasons that this large group may at some time in the future become to a degree mobile, most of the 23 subjects referred to were in effect bedfast at the time of the survey. On the other hand, only one-third of the group was mobile, with or without the use of a walking-aid.

9.2 FAMILY RESIDENCE AND SUBJECTS' USUAL PLACE OF RESIDENCE

Half of the families of this population lived in the Brisbane metropolitan area, while 20 and 28 per cent respectively lived in other urban and rural areas. However, the usual place of living for the children and young people ranged from a long-term hospital or institutional setting (34, or 87.2%) to the family home for 4 subjects (10.3%) and a residential school location for 1 subject.

The long-term hospital and institutional settings included Challinor Centre (7, or 18.0%) and the Basil Stafford Centre (1, or 2.5%), which are training centres for intellectually handicapped adults and children respectively. Six subjects (15.4% of the group) lived at the W. R. Black Home for Crippled Children, a church organisation, also for the intellectually handicapped. The remaining 3 locations, catering together for half of the subjects (20, or 51.3%), are units for severely and profoundly handicapped children attached to hospitals.

Details of position in, and size of, family, family parental status and family socio-economic status, when compared to data set out in Chapter 4 for all 240 cases surveyed in the study, showed no major differences.

9.3 SUMMARY AND DISCUSSION

This group of spina bifida and/or hydrocephalic subjects in long-term care is a fairly diverse one. The age distribution probably reflects recent surgical techniques to counteract the effect of hydrocephalus. One-third of the subjects were mobile; the remainder were dependent in mobility or were bedfast at the time of the survey. Most lived in institutional long-term care settings, but a few were living at home. Those not at home were divided between training-centre placements for the intellectually handicapped and special units in hospitals where nursing care was the major treatment mode.

Within the funding and time limits of this study it was not possible to make a detailed examination of the treatment and developmental needs of this group. Those in training centres for the intellectually handicapped were located in units where not all children received full- or part-time educational services. Those in units attached to hospitals were similarly placed, in that nursing and medical care is typically provided at a high standard, but therapeutic services and education programs are minimal or not available. However, the majority of these children and young adults formed part of a much larger group of handicapped persons identified in a study carried out following this research project. In that study (Andrews, Elkins, Berry & Burge 1979), a total of 374 residents aged 20 years and under, residing in Health Department long-term care residential facilities in Queensland, were identified, 307 of whom were aged between 5 and 18 years. One of the important findings about this group was that 78.17 per cent were not in receipt of full-time school programs. It is to be expected that the 25 children and adolescents with spina bifida and/or hydrocephalus under discussion were equally affected by this situation, if not more so.

For some years it has been a sad commentary on provisions for this group of children in most States of Australia that such a lack of developmental and educational services exists in long-term care facilities. There is ample evidence from practice in other countries to show that severely and profoundly handicapped children can benefit significantly from these services. Approaches to meeting their educational needs have been discussed elsewhere (Andrews 1979).

However, the full impact of the disabling conditions experienced by this group of severely handicapped children and adolescents, and the implications of those conditions for treatment in a wide range of areas, could profitably be the subject of further research. Such research should be concurrent with increased efforts to provide adequate therapy, stimulation or training aimed at reducing the effects of long-term hospitalisation and promoting the development of potential for social responses and skill development.

CHAPTER 10

THE FUTURE OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS IN AUSTRALIAN SCHOOLS

The educational needs of children with spina bifida and hydrocephalus have been the central theme of this report. It has also placed emphasis on the family–social environment of the students and on the experiences reported by parents and teachers in their efforts to assist development. The home and school settings are important to that development, as are the medical intervention, treatment and therapy services discussed. All contribute to the effective management of the special disabilities, health and education needs of this group.

The study has identified a high level of acceptance and integration of these disabled students in regular schools, which offer an alternative educational location to special schools. Their placement in regular schools, however, is largely brought about by family action. Even so, a proportion of the group identified as experiencing spina bifida and hydrocephalus, particularly those with more severe handicaps, continues to be located in special schools. It seems clear that future practice will confirm that both types of schooling are important for some students, but a better understanding of the numbers and location of students with spina bifida and hydrocephalus, their educational, social and medical characteristics and needs, and those needs relating to their families and teachers, holds promise of significantly increasing the benefits of schooling and related services for each child.

One important characteristic of the study was this attempt to provide a comprehensive account of a group of disabled children about whom little was known. While spina bifida has been studied extensively in the United Kingdom, little study has been made in Australia of the long-term effects of the adoption of surgical procedures which permit the survival of increasing numbers of children born with neural tube defects. Parent organisations for this group of children are not strong in this country, compared to those established to assist children with other physical or intellectual handicaps; and in Queensland the parent organisation did not seek to provide the separate special schooling which was typical of organisations for other handicapped groups, such as the cerebral-palsied.

The research reported casts some light on the influence of voluntary organisations on the provision of such separate services, but a more systematic comparative investigation needs to be carried out. Children with cerebral palsy or intellectual handicap in Queensland are frequently assisted by voluntary organisations which, with the passage of years since their formation, have retained little parent input. In some respects, these organisations have taken on many of the characteristics of government departments. On the other hand, the Spina Bifida Association of Queensland is heavily parent centred, though parent involvement and advocacy are limited by the small size of the group. It appears that the dependence on specialised medical services in the community, and the family stress of raising a spina bifida child who will typically be severely multiply handicapped, force the parents involved towards a mutual-help function and away from vigorous advocacy and sustained fund-raising for the provision of extensive services. One consequence of this has been the absence of a thrust towards centralised services — a characteristic result with organisations for other disability groups — with attendant separation of the children from regular education, followed later by deliberate integration.

The needs of Queensland children with spina bifida and hydrocephalus have not been fully understood in the past. Indeed, until the present study, neither the parent group nor the State education authority were able to speak with any certainty of the nature and extent of such needs. However, their recognition of this fact led, in part, to this investigation. A further characteristic of the study, which distinguishes it from overseas research, is the attempt to identify and describe all children in the State of Queensland who were known to have spina bifida and/or hydrocephalus. While there is no simple way of verifying the results of this effort, it is our view that a reasonably complete account has been made. One of the disappointments of the study was the lack of complete, consistent and easily interpreted medical records to permit a retrospective analysis of medical treatment data for the subjects in relation to more recent findings on educational and developmental status. Such a study urgently needs to be carried out, but until such time as more comprehensive and comparable medical record systems are in use, it will be difficult to obtain this type of data for research and the forward planning of educational facilities and programs.

10.1 FAMILY ASPECTS

One important factor identified in the study was the tendency for families to reside in cities more frequently than expected, based on demographic patterns in Queensland. It appears to be necessary for families of spina bifida children to move from rural areas in order to obtain services, although we did not obtain conclusive evidence on this matter. When the above observation is coupled with the fact that over a third of the children identified did not live at home, there is a strong case for examining whether medical therapy and educational services can be provided much closer to the usual residence of families and in the regions in which a spina bifida or hydrocephalic child is born. Where this is not possible — and because of the size and dispersed population of Queensland and most other States this will not be infrequent — assistance with travel costs is important to minimise the financial strain on parents in achieving essential services. It could also be noted that available welfare services frequently are advertised poorly and can involve parents in such bureaucratic entanglements that they may not avail themselves of them. The high degree of stress experienced by families of spina bifida and hydrocephalic children requires that programs of assistance should not create extra demands upon the parents.

Even though the socio-economic indices for the families in this study do not show an over-representation of the less affluent, a considerable measure of support is required by most families to help meet the extra costs of aids and appliances, special clothing and other items which become a recurring burden as children grow. The costs associated with moving residence to obtain services, and of altering homes to provide for wheelchairs and other amenities, need to be reimbursed. The particular problems of many Queensland homes, built on an elevated foundation, are a somewhat unique consideration.

Some important needs of families, relating to medical services, were identified. The wide range of people who provide initial advice and who discuss with parents their newborn spina bifida infant remains a source of concern. Medical services, which are the primary source of assistance to families in the child's first weeks of life, should ensure that consistent and comprehensive policies for informing parents about the birth of a disabled child and involving them in decision making about the child, are universally carried out. Furthermore, parents typically need repeated occasions for discussion of the implications of having a handicapped child. Consideration should be given to whether nursing staff could adopt a more central role in this counselling process, particularly if this occurs as part of their natural contact with the mother in the maternity wards. Support must be on a continuing basis, must allow for 2-way discussion and the seeking of advice, and must provide an atmosphere in which parents and professional staff can maintain productive communication. It was noted, for example, that only one-third of the parents interviewed felt that they understood the initial information they were given about their infant, while a smilar proportion was not satisfied with the amount of information received. These considerations, along with the change in attitude to their handicapped child over time, which was reported by almost 80 per cent of the parents, point to the need for high quality long-term counselling and information services to mothers and families of newborn disabled children.

Hospital services have achieved a considerable degree of success in providing a comprehensive range of services for infants and children with spina bifida and hydrocephalus. Nevertheless, attention needs to be given to associated services in hospitals, which at present are an inconvenience to the parents of handicapped children and an unnecessary burden on them. The timing of appointments, actual access to hospitals, the co-ordination of clinical services, and aspects such as the availability of parking and toilets and access to these facilities, warrant attention.

The provision of medical services also needs to be accompanied by mechanisms whereby families are appropriately involved at all stages of treatment. Almost half of the parents interviewed in this study were not consulted before initial surgery on their child. Adequate opportunities for the exercise of parental rights of participation in such decisions are a clear priority, as is participation as part of the care and management team. Parent live-in facilities are a much needed addition to hospital facilities and they would benefit both parents and children. Parents should have access to training in management techniques relevant to handicapped children, rather than being cut off from the early care of their child.

Considerable similarity exists between the social data reported in this study and that published by Anderson & Spain (1977). Like them, we find that parents need information on the condition with which their child has been born, advice and help with management of the child at each successive stage of development and treatment, and continuing support through the periods of stress which will surely be experienced. Our findings indicate that while some parents' needs are being met, there are many who expressed concern at lack of consideration in these areas. Professional support must ensure that parents provide appropriate developmental stimulation for their handicapped infant and must help them to learn to manage their child in the light of accepted developmental criteria. To this end, the enrolment of spina bifida children in regular pre-school education was encouragingly widespread in Queensland. We speculate that the ready availability of free pre-school education, the interest of parents, and the policy of the Queensland Education Department of encouraging the attendance of handicapped children at pre-school, and providing advisory services to pre-school teachers, are largely responsible for this situation.

10.2 EDUCATIONAL ASPECTS

The present study has provided information on the 'natural' integration of many handicapped children into an education system largely unaware of them. This has enabled an analysis of factors related to parent-initiated regular school placement of handicapped children, and has given some knowledge of the responsiveness of schools to the problems created by such placement. On the other hand, it has highlighted the need for educators to be more aware of changing patterns of handicapping conditions in schoolchildren and their significance for planning of the special education services progressively required.

The lack of adequate planning for the increased numbers of children with spina bifida and hydrocephalus in recent years may all too easily be repeated in the future. Changes in medical practice (advances, it is hoped; but the memory of Thalidomide is fresh) often mean changes in the numbers and types of handicapped children in the community. A formal mechanism is needed to co-ordinate medical and educational service delivery systems and to provide advice on, and monitor, the changing pattern of disability. A committee established to enhance such educational planning could also follow up changes in the services provided and examine the effectiveness of facilities and policies. Where the policies involve selective medical treatment, as is now commonly the case, findings could effectively be related to the moral and ethical issues involved.

It was noted that there was a lack of co-ordination between guidance services in Queensland schools and the support services of the Spina Bifida Association. Visiting teachers were judged to have case-loads which made it difficult for them to overcome these communication problems. Further, these support services mainly responded to parent initiatives, rather than undertaking planned development of a coherent range of services. Thus, parents were noted as playing a major role in the enrolment of their children at regular schools and as making an essential contribution in transporting them to and from school and managing continence during the school day.

Despite the limitations in co-ordination of support services noted above, the school placement procedures based on parent action have proved to be satisfactory in that few of the children enrolled in regular schools were regarded by their teachers as being better placed if they were enrolled in special schools. However, the degree of effort and negotiation by parents involved in achieving placement in regular schools is still not clear, nor how readily some children in special schools, particularly those associated with hospital or medical services, could have been given a more normalising educational setting if co-ordinated placement procedures had been available. Such a question deserves further attention.

While many of these disabled children in regular schools were adequately provided for, notable gaps in provision were observed for some. Overall, as mentioned above, the visiting-teacher service for physically handicapped children is spread too thinly, especially in rural areas. Considerable developmental risk can occur when the parents and regular class teachers act separately, and with limited expertise, to provide a total education and management program. Additional, more frequent and more intensive assistance is needed, including the provision of special furniture and equipment and teacher aids in regular schools enrolling severely handicapped children and more frequent contacts with the visiting-teacher service. Few regular schools are adequate to meet the mobility needs of handicapped students; emphasis needs to be given in the design of schools to assist children with physical and other handicaps. The costs of modifying existing schools to provide accessibility and suitable toilets would be kept to reasonable limits if one regular school in each locality or district were modified in the first instance. At least, this would better provide for the more severely handicapped children and bring the social and academic advantages of attending regular schools closer to reality.

The issue of whether handicapped children should attend regular or special schools has been examined in a somewhat novel way in this report. In most cases where the degree of handicap was not severe, parents initially planned in terms of regular schooling and sought a school that would accept their child. The absence of an obvious special school alternative for spina bifida children probably served to minimise pressures towards segregated placement. Educational policies should seek to ensure placement of handicapped children according to educational needs, not categorical groupings or existing provisions. Certainly the evidence from this study points to the successful integration of spina bifida children, even with present levels of support, but long-term policy cannot depend so heavily on *ad hoc* procedures and the goodwill and dedication of parents and teachers; it must be concerned with ensuring the adequacy of education within regular schools for spina bifida children. The provision of therapy and special education support to spina bifida children and their teachers in regular schools, and the preparation of teachers for this role, are pointers to the adequacy of provisions.

From the study of student abilities and school achievements it was found that the range of intelligence and other cognitive test scores among the children with spina bifida and hydrocephalus in regular schools was very similar to that of non-handicapped children, with the well-known performance (non-verbal) deficit being the main area in which scores were depressed. Academic achievement was, if anything, slightly better overall than would be expected according to I.Q. prediction, and certainly at a level commensurate with age and grade. Teacher opinion, and observation during the research, suggested that in most cases the personal and social development of these students was satisfactory.

Little evidence was found, in regard to the children in regular school placements, to support sex differences in school performance, or the hyperverbalism or 'cocktail party' syndrome frequently claimed for these children, though clinical observation suggested that hyperverbalism may have been present among some of the special school children. However, visual motor co-ordination problems, highlighted in other recent research, were established. It is not clear whether these fine motor difficulties have an organic basis or whether they result from experiential lack. It is suggested that teachers should pay special attention to the development of fine motor skills in children with spina bifida and that systematic handwriting instruction be adopted. However, further research is urgently needed in this area, and this will require an extensive standardisation of a range of fine motor–manipulative assessments.

10.3 FINAL COMMENTS

One important feature of the present study was its attempt to identify all children in the State of Queensland who were diagnosed as manifesting spina bifida or hydrocephalus. This presented several problems, especially as a central register of children with handicapping conditions is not maintained. These included that, by seeking children from birth into young adulthood, we stretched beyond the normal bounds of the education system. However, by including Catholic and other non-government schools in our target group, all of which are less centralised in their administration, we sought children in other than the major placement agency for school-age physically handicapped children, that is the Queensland Education Department. By locating children throughout the State, we were also able to include many who tend to be omitted from such studies because of distance. By searching for institutional placements, we were able to identify an important and often overlooked group of severely or profoundly handicapped children with these disabilities.

It is clear, however, that we have not exhausted the questions which should be answered concerning children and adolescents with these conditions. The problems which made it difficult to ensure the identification of all children in the State remain, and those caused by population mobility may well increase. We do not know to what extent survival of affected children, and the provision of adequate services, are dependent on distance and geography but we consider that the size and the imbalance of population within Queensland may be important factors.

We remain concerned that it was not possible to obtain useful information from medical records in order to relate a variety of perinatal factors and early treatment decisions with developmental outcomes. Research of this type requires close collaboration among medical, social welfare and educational practitioners, but there is much to be gained by pursuing such collaboration in research and in practice.

It is true that the lack of foresight by medical and educational authorities has permitted the educational placement of spina bifida children without adequate planning. In future years it will be important that the needs of adolescents and adults handicapped with spina bifida or hydrocephalus are anticipated. The number of adults identified in the present study was small, but larger groups of children are moving through pre-school and the primary-school years into secondary school. These changes will require shifts in the nature of services provided.

The prevalance of survivors of neural tube defects has continued to increase in Queensland over the past decade. It has been suggested that the blood alphafetoprotein test will provide a routine check (which amniotic fluid testing is not) on the existence of such defects and that resultant pregnancy termination will reduce spina bifida births.

Whether trends emerge in the future management of spina bifida children, careful monitoring is still indicated to ensure that handicapped infants face a future in which services are planned to meet their needs.

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